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University of Glasgow

Responding to Stress and Distress in Young Onset Dementia: an
Interpretative Phenomenological Analysis of a Biopsychosocial Group
Intervention for Carers

And Clinical Research Portfolio

Craig Frank Wilson, BSc Psychology with Biological Sciences (Hons.)

Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

September 2017



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Firstly, I would like to thank the carers who gave up their time to speak to me and who made this study possible. I appreciate you sharing your stories, challenges and concerns. It was also inspiring to hear about the difficulties you had overcome. There was so much I could have written about from your accounts. I hope the findings from this study will benefit all those that are living with a family member with young-onset dementia (YOD).

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Chapter 1: Systematic Literature Review

Experiences of young people with a parent with Young-Onset Dementia (YOD): A qualitative systematic review

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Abstract

Background: The diagnosis of Young-Onset Dementia (YOD) within a family represents a difficult period for family members to adapt to. Current research focuses on spousal or whole family experiences. Although this research includes several literature reviews, these reviews have not focussed specifically on the unique experiences of children of all ages of an affected parent. **Aims:** The review explored the impact and experiences of caregiving and family relationships of children with a parent with a diagnosis of YOD, providing a synthesis of qualitative research in the field. **Methods:** A systematic search was conducted using multiple electronic databases, reference lists of included studies and hand-searching of relevant journals. This identified 15 studies for inclusion, which were evaluated for quality. The synthesis was conducted using meta-ethnography. **Results:** Six interrelated themes were identified, including: a) making sense of dementia; b) changes in relationships (from within the family and socially); c) the emotional impact of caregiving; d) implications for developmental stages; e) support (social, family and services); and f) coping through time and growing. **Discussion:** YOD presents challenges to children and young adults in terms of understanding, relationships, adjustment and coping. Unique difficulties to this age demographic are discussed alongside the implications to future research and service provision.

Keywords: Young-Onset Dementia; Qualitative; Literature Review; Meta-Ethnography; Young People; Carers.

Introduction

Young Onset Dementia (YOD) is a term describing those who are diagnosed with dementia before the age of 65. Prevalence estimates are variable and range between 0 and 700 per 100,000 people (Viera et al., 2013). In 2013, it was estimated that there were around 42,325 people in the UK with YOD (Alzheimer's Society, 2014). Many of these individuals remain at home with the assistance of family carers. During this time, carers can experience psychological difficulties from their caring role, such as increased levels of burden and mental health difficulties (van Vliet et al., 2010; Svanberg, Stott, & Spector, 2011), which are similar to caregivers of people with late-onset dementia (LOD; Brodaty & Berman, 2008).

Whilst families of people with YOD may experience similar situations and challenges as families with older people diagnosed with LOD, the younger group may have additional challenges and considerations. For example, families are more likely to face financial and employment difficulties (van Vliet et al., 2010), and have dependents living at home who can find the change in relationships distressing (Roach et al., 2008). In addition, they also face more varied presentations, more severe and pervasive symptoms, and increased behavioural changes in the affected family member (Mendez, 2006; Millenaar et al., 2016). In terms of service provision, a recent systematic review has highlighted several difficulties including obtaining a diagnosis and gaining appropriate support (Millenaar et al., 2016), all of which have an impact on caregivers.

Much of the literature surrounding carers of people with YOD focuses on the psychosocial impact of caregiving and is mainly qualitative in nature. Research concentrates on the experiences of whole families and spouses, and includes several literature reviews (Roach et al., 2008; van Vliet et al., 2010; Svanberg, Stott, & Spector, 2011). Less attention is paid to the differences in experiences within different generations, especially with children of different ages. These children are often unseen within services (Gelman & Greer, 2011), and so their needs and experiences may go without direct consideration. This can lead to particular difficulties for younger people, who may find themselves more isolated than their parent-caregiver (Svanberg, Stott, & Spector, 2011).

Young carers

There is a growing recognition in the literature that children, adolescents and young adults provide extensive support and care to parents with mental and physical health problems. In Scotland, it is estimated that 93,000 young people provide care (Scottish Government, 2017). A review by the Scottish Government (2017) has highlighted the impact this can have on their physical and mental health, well-being, education and employment. There is also evidence that caring can affect friendships and relationships (Rose & Cohen, 2010).

Young carers in YOD

YOD can present within different individual and family developmental stages (Erickson, 1959; Dellman-Jenkins, Blankemeyer & Pinkard, 2001). For example, YOD may appear during adolescence, when young people focus on developing peer relationships. However, it may also appear during the young adulthood period where tasks of individuation from the family unit and leaving home to pursue their own family and careers are important. At present, there has not been a systematic review conducted into the experiences of young people (from young children to adults) who have a parent with YOD. Therefore, the current proposal aims to explore the experiences of this sub-group of the family.

Aims

The current review aims to explore the impact and experiences of caregiving and family relationships of children with a parent with a diagnosis of YOD. The review will provide a qualitative synthesis of the research and evaluate the quality of existing research in this area.

Methods

Search Strategy

Several electronic databases were searched using set terms that were refined for the final search (conducted April 8th, 2017), ensuring that the strategy was sufficient to gather relevant papers. The search string involved the following:

1. Dementia OR Alzheimer*; AND
2. (early onset OR early-onset OR “EOD”) OR (young onset OR young-onset OR “YOD”) OR presenile OR “working age” OR under 65; AND
3. child* OR adolescent* OR teenage* OR young* OR parent*; AND
4. carer* OR caregiver*

Truncation was used to allow for variations within keyword endings. Electronic databases included those for published literature (CINAHL, EMBASE, Medline, PsychINFO, Scopus, Web of Science) and unpublished literature (ETHOS, OpenGrey), and searches were not limited to publication year. Searches of reference lists and a hand search of key journals (International Psychogeriatrics, Dementia) were also conducted.

Inclusion/Exclusion Criteria

Studies were included if they:

- (a) were qualitative or mixed-methods designs;
- (b) were written in English;
- (c) involved children, of any age, of a parent with a diagnosis of YOD;
- (d) explored experiences of care-giving;
- (e) were accessible.

Studies were excluded if they:

- (a) were quantitative research, intervention studies, literature reviews or non-studies such as conference abstracts, or inaccessible;
- (b) were not written in English;
- (c) focussed on non-YOD specific groups (e.g. Down’s syndrome, etc.);
- (d) included mixed samples or experiences from other family members’ perspectives;
- (e) did not explore caregiving experiences;

Outcome of Search Strategy

The search strategy identified 467 papers from electronic sources. After removing duplicates, 43 potential papers were identified based on paper title. A further eight papers were included from additional searches. 24 papers were excluded based on the abstract review. Where it was unclear as to whether a study was to be excluded, papers were retained for full-text review. The remaining 31 papers were further screened against inclusion criteria. For five papers, a second opinion for inclusion was sought from the research supervisor. This resulted in 15 papers that met inclusion criteria. A summary of this process can be found in Figure 1.1.

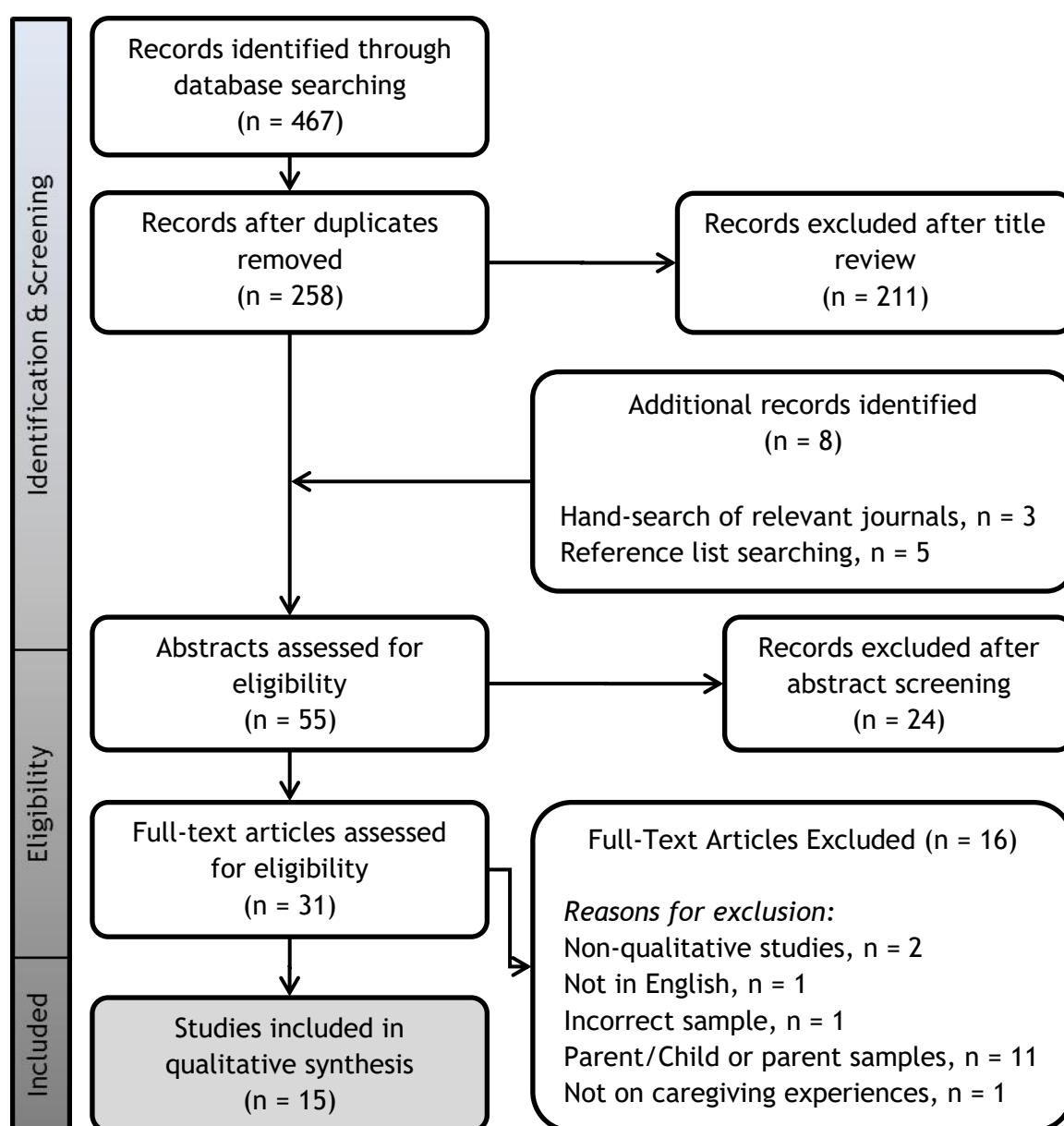


Figure 1.1 - Flowchart representing the review search strategy process

As qualitative research is a diverse field, representing a variety of data collection methods, analytical approaches and interpretation paradigms (Walsh & Downe, 2006), several methods of assessing quality exist (Cohen & Crabtree, 2008); however, there is no consensus on an approach to quality reviewing or, indeed, whether it is appropriate within qualitative research (Dixon-Woods et al., 2005). Walsh & Downe (2006) generated 12 essential criteria from a meta-synthesis of eight existing quality frameworks. This framework was utilised in the present review to assess the quality of identified studies (Appendix 1.1). Given the subjective nature of quality ratings in qualitative research (Dixon-Woods et al., 2006), the framework was interpreted flexibly to consider the strengths and weaknesses of included studies. Studies were assigned a total score, based on the level of adherence to the specific prompts within each criteria, from 0 to 3 representing 'unmet', 'some aspects met', 'most aspects met', or 'fully met', respectively. In order to highlight studies that demonstrated strengths across most of the quality criteria, the lead researcher designed a categorisation system based on the overall adherence to the quality framework. Total scores of less than 50% were considered to be poor quality, with up to 75% being satisfactory, and studies meeting most of the specific prompts and criteria (over 75% adherence) being of good quality. Given the subjective nature of scoring qualitative studies, a Trainee Clinical Psychologist, independent of the review, rated a sample (seven papers) of the included studies. Agreement regarding the absence or clear presence of individual criteria across sampled papers was 87%, with discrepancies being resolved following discussion.

Analysis

A review of qualitative synthesis approaches indicated at least nine distinct approaches (Barnett-Page & Thomas, 2009). Meta-ethnography (Noblit & Hare, 1988), an approach that involves re-interpretation and developing a cumulative understanding of multiple studies, was selected to synthesise papers in the review. Although some aspects of meta-ethnography are not well-defined, a number of papers elaborate on the process (Atkins et al., 2008; Toye et al., 2014) and these were used as a guide (Appendix 1.2).

Data extracted included quotations, themes, and author interpretations from the results and discussion sections. Where studies used the same participants (highlighted in orange in Table 1.1), the findings from the papers were considered together before comparing with other studies to reduce participant duplication. The researcher read individual papers several times to become familiar with the content and context, noting themes in Microsoft Excel. Themes were then compared across papers, generating a grid of conceptual similarities and differences. The papers were then compared in chronological order, with the generated synthesis being re-interpreted with successive papers, resulting in a combined understanding of themes ('line of argument' synthesis). Finally, a new thematic framework was developed from the synthesis to explain concepts within and between papers.

Results

Quality

Individual ratings for study quality are provided in Table 1.1 and Appendix 1.3. Four studies were considered good quality (Garbutt, 2006; Allen, Oyeboode, & Allen, 2009; Lord, 2010; Aslett, 2014), ten were satisfactory (Svanberg, Stott, & Spector, 2010; Nichols et al., 2013; Barca et al., 2014; Millenaar et al., 2014; Johannessen, Engedal, & Thorsen, 2015; 2016; Gelman & Rhames, 2016; Sikes & Hall, 2016; Hutchinson et al., 2016a; 2016b), and one study was identified as poor (Davies, et al., 2000). A summary of strengths and weaknesses is provided below, with more comprehensive detail found in Appendix 1.4.

Strengths included that all studies provided sufficient detail into the purpose of their study, providing context through the existing literature, although none demonstrated a systematic approach to finding this literature. All but one study (Davies et al., 2000) used extensive quotations to support their interpretations.

Conversely, most studies provided insufficient or no details of researcher reflexivity, and several studies provided limited information regarding ethical concerns (Davies et al., 2000; Nichols et al., 2013; Millenaar et al., 2014; Gelman & Rhames, 2016). There were also several concerns with regards to potential bias within studies. Four studies (Aslett, 2014; Sikes & Hall, 2016; Hutchinson et al., 2016a; 2016b) used a single sampling strategy or did not provide sufficient details of this. In one study (Nichols et al., 2013), the primary author's children were in the sample. Although they provide details of removing biased information from analysis, there remains a risk of bias.

Given that the highest quality papers were predominantly the unpublished theses, the quality of the written account may be based on presented information rather than quality of the study.

Synthesis of Included Studies

Omitting participant duplication, included studies (Table 1.1) explored the experiences of 149 young people with a parent with YOD; however there was marked heterogeneity within studies in terms of age, time since diagnosis and living circumstances. Only three studies (Svanberg, Stott, & Spector, 2010;

Nichols et al., 2013; Gelman & Rhames, 2016) sampled predominantly adolescents, whereas other study samples comprised of participants between the ages of eight and 37 years. Thus, the analysis of age-specific differences was often difficult to ascertain. Therefore, the classification of ‘young person’ covers children, adolescents and adults. Where appropriate, differentiation of age groups is indicated by the use of specific terms identified above. There were wide variations in the time since diagnosis both within and between studies, spanning 0 to 19 years, and several studies did not provide these details (see ‘Demographic Information’ in Table 1.1). This was also true of information regarding living circumstances of both the young person and their affected parent. Although potentially influential, the current synthesis was unable to determine the influence of such variables on the results.

The generated synthesis comprised of six interconnected themes and respective sub-themes, spanning the period before, during and up to 19 years after their parents’ diagnosis (Figure 1.2). Included studies varied in their contributions to generated synthesis themes. Details of this variation can be found in Appendix 1.5. In addition, an example of a generated synthesis theme and the themes/concepts from contributing papers can be found in Appendix 1.6

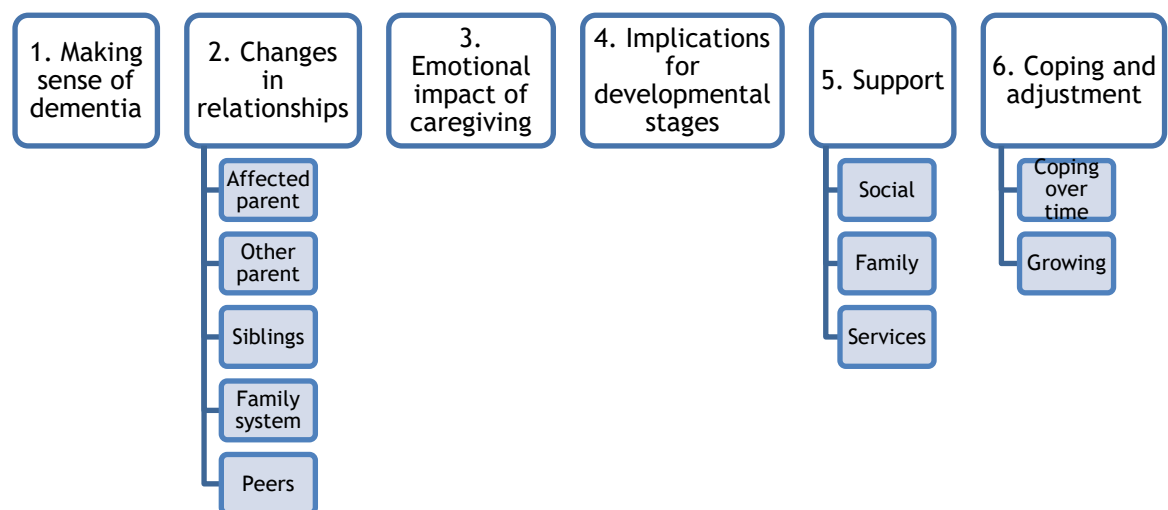


Figure 1.2 - Themes and subthemes from the meta-ethnographic synthesis

Table 1.1 - Details of included studies and respective quality ratings

Author Year Country	Demographic Information		Analysis	Identified Themes (superordinate themes only)	Quality % Rating
	Participants	Affected Parent			
Lord (Thesis) 2010 UK	Interviews with 7 of the young adults from Allen and colleagues' (2009) study (aged 17-28; 4 females; 4 living at home), 3-9 years after parents' diagnosis.	Mixed diagnoses (AD, n=1; FTD, n=2; mixed, n=3; VaD, n=1) with 5 in care and 2 deceased.	Constructionist Grounded Theory	<ul style="list-style-type: none"> • Coping, adapting, roles and strain • Grieving • Questioning, making sense and the future • Growing 	91.7% <i>Good</i>
Garbutt (Thesis) 2006 UK	Interviews with 5 young adults (aged 23-37; 4 females; 3 living at home) between four months and three years since parents' diagnosis.	Mixed diagnoses (AD, n=4; Pick's disease, n=1), all living at home.	Interpretative Phenomenological Analysis	<ul style="list-style-type: none"> • Changes in relationships • Understanding change in dementia and self • Managing changes in family and self • Change in self 	88.9% <i>Good</i>
Aslett (Thesis) 2014 UK	Interviews with 5 young adults (aged 25-36; 3 females), 1-5 years following parents' diagnosis.	Mainly AD but not specified).	Interpretative Phenomenological Analysis	<ul style="list-style-type: none"> • Relationship changes • Changes in roles and responsibilities • Supporting the other parent • Support for self • Impact of living with genetic risk 	83.3% <i>Good</i>
Allen, Oyebode & Allen 2009 UK	Interviews with 12 young adults (aged 13-24; 7 females; 10 living at home), 2-6 years after parents' diagnosis.	Mixed diagnoses (AD, n=4; FTD, n=2; mixed, n=3; VaD, n=3) with 10 living at home.	Grounded Theory	<ul style="list-style-type: none"> • Damage of dementia • Reconfiguration of relationships (Loss) • Strain, stigma, and worry • Caring in the family and care homes • Coping (problem, emotional) 	77.8% <i>Good</i>

Author Year Country	Demographic Information		Analysis	Identified Themes (superordinate themes only)	Quality % Rating
	Participants	Affected Parent			
Svanberg, Stott & Spector 2010 UK	Interviews with 12 adolescents (aged 11-17; 6 females), roughly 1-7 years following parents' diagnosis.	Mixed diagnoses (AD, n=5, Pick's disease, n=2; VaD, n=1) with 2 in care and 2 deceased.	Constructionist Grounded Theory	<ul style="list-style-type: none"> Discovering dementia Developing a relationship with affected parent Learning to live with it Going through it together 	75.0% <i>Satisfactory</i>
Gelman & Rhames 2016 USA	Interviews with 8 adolescents and young adults (aged 13-20; 5 females), between 0 months and 13 years since parents' diagnosis.	No information given.	Thematic Narrative Analysis	<ul style="list-style-type: none"> Disruption to development and relationships Adaptation, coping and growth Lack of resources and specific services 	75.0% <i>Satisfactory</i>
Johannessen, Engedal, & Thorsen 2016	Interviews with 14 young adults (aged 18-30; 9 females), between 6 months and 10 years after parents' diagnosis.	Diagnoses not specified, with 6 living at home, 7 in care.	Grounded Theory	<ul style="list-style-type: none"> About the disease About the self (emotional chaos) About the parent (role reversal) About others (a battle) 	72.2% <i>Satisfactory</i>
Johannessen, Engedal, & Thorsen 2015 Norway			Steger's three-step method for analysing metaphors	<ul style="list-style-type: none"> Coping through detachment Coping through resilience 	69.4% <i>Satisfactory</i>
Barca 2014 Norway	Interviews with 14 young adults (aged 20-37; 12 females), over 4 years after parents' diagnosis.	Mixed diagnoses (AD, n=5; FTD, n=4; mixed, n=1; brain damage, n=2; tumour, n=1), with 3 living at home, 10 in care.	Modified Grounded Theory	<ul style="list-style-type: none"> Social relationships Experiences and needs related to services 	66.7% <i>Satisfactory</i>

Author Year Country	Demographic Information		Analysis	Identified Themes (superordinate themes only)	Quality % Rating
	Participants	Affected Parent			
Millenaar 2014 <i>Netherlands</i>	Interviews with 14 young people (aged 15-27; 8 females)	Mixed diagnoses (AD, n=5; FTD, n=4; VaD, n=1).	Inductive Content Analysis	<ul style="list-style-type: none"> • Impact of dementia for young person • Coping with the disease • Need for care and support 	66.7% <i>Satisfactory</i>
Hutchinson et al. 2016a <i>Australia</i>	Interviews with 12 young people (aged 10-33; 11 females), 2-19 years after parents' diagnosis.	No information given.	Thematic Analysis using Framework Analysis	<ul style="list-style-type: none"> • Emotional toll of caring • Keeping the family together • Grief and loss • Psychological distress 	63.9% <i>Satisfactory</i>
Hutchinson et al. 2016b				<ul style="list-style-type: none"> • Invisibility • Connectivity • Being empowered 	63.9% <i>Satisfactory</i>
Nichols et al. 2013 <i>North America</i>	Two online focus groups with 14 children and adolescents (aged 8-18; 10 females), 1-5 years after parents' diagnosis.	Mixed Diagnoses (FTD, n=13; PPA, n=1).	Thematic Analysis	<ul style="list-style-type: none"> • Emotional impact of living with an affected parent • Caregiving • Coping • Symptoms • Diagnosis • Relationships • Support 	61.1% <i>Satisfactory</i>

Author Year Country	Demographic Information		Analysis	Identified Themes (superordinate themes only)	Quality % Rating
	Participants	Affected Parent			
Sikes & Hall 2016 UK	Longitudinal study, interviewing 19 young people (aged 8-31; 16 females; 5 at home, 10 out of home), 1-11 years after parents' diagnosis.	Mixed diagnoses (LBD, n=1; FTD, n=6; VaD, n=2; PCA, n=1), with unspecified numbers deceased or in care.	Thematic Analysis	<ul style="list-style-type: none"> • They had to Hollywood it • A different person • They do not know me • They are not very nice aggressive, suspicious • They cannot talk to me 	58.3% <i>Satisfactory</i>
Davies et al. 2000 USA	Interviews with 20 young adults (aged 16-34; 14 females; 2 living at home).	All with AD and living at home.	Grounded Theory	<ul style="list-style-type: none"> • Awareness • Explanation • Attribution • Integration 	47.2% <i>Poor</i>

AD = Alzheimer's Disease, FTD = Frontotemporal Dementia, VaD = Vascular Dementia, PPA = Primary Progressive Aphasia, LBD = Lewy Body Dementia; PCA = Posterior Cortical Atrophy

Note: Papers using the same samples are highlighted in orange.

1. Making sense of dementia

Eight studies (including four deemed to be of good quality) highlighted that whilst young people were adjusting to the affected parent's diagnosis; they either actively attempted to make sense of dementia or avoided doing so. With the former, they reflected on missed signs and behaviours (Garbutt, 2006). Some young people searched for causes; drawing upon helpful information such as prior experience of dementia within the family, or unhelpful information such as blaming situations or themselves for the onset (Lord, 2010).

"You start to look back sometimes and think 'was that thing that didn't seem out of place at the time actually something to do with the progression of the illness'..." (Garbutt, 2006)

Personal risk with regards to behavioural symptoms and being unprepared for these was also described (Gelman & Rhames, 2016). Contributing to the difficulties was their lack of understanding about dementia, and the belief that it is *"for someone who is old, not for fifty-three"* (Aslett, 2014). For adolescents, Svanberg and colleagues (2010) highlighted how young people may not be aware of dementia symptoms as it was something that they had *"grown up with"*.

2. Changes in relationships

a. Affected parent

All studies explored the experience of losing the 'real' parent. The *'not the same person'* narrative was pervasive; for example, one participant in the Gelman & Rhames' (2016) study recognised this in her father's painful comments: *"my [healthy] dad would never say that to me"*. Holding on to the 'real' parent, both cognitively and via practical roles, was sometimes helpful (Svanberg, Stott, & Spector, 2010); providing a sense of comfort and helping to process emotions (Nichols et al., 2013). Others struggled to adjust to the loss of the 'real' parent, looking for signs of preservation or continuing to dismiss dementia (Lord, 2010), distancing themselves, experiencing negative emotions towards the parent and relating difficulties to the parent's true 'self'.

“...it makes someone who was a lovely character really easy to dislike and you have to really fight not to hate your own parent.” (Sikes & Hall, 2016)

All of the good quality studies indicated that the premorbid parent-child relationship appeared important for *how* loss is experienced. The onset of YOD can prevent reconciliation of relationships (Aslett, 2014); however, there was also evidence for a closer relationship following dementia (Garbutt, 2006). Adolescents, who could not recall their parent prior to the disease, also experienced a sense of loss (Gelman & Rhames, 2016).

Role reversals occurred in both a practical (e.g. duties and responsibilities) and perceptual manner, with young people taking on tasks including personal care. One participant remarked how life *had “gone full circle”* (Gelman & Rhames, 2016), and another how *“it became a great role change”* (Barca et al., 2014). Participants also iterated viewing their affected parent as ‘child-like’. Overall, the change in the affected parent-child relationship was complex, with some young people able to adjust whilst others struggled.

b. Other parent

Eight studies (including all good quality studies) identified the concerns and fears of young people for the well-being of their other parent and recognised the responsibility placed on them to provide care.

“She is under too much stress. She has to go to work, run the house and everything, she has to clean the house and everything, and she has not got enough time.” (Allen, Oyebode, & Allen, 2009)

In Svanberg and colleagues’ study (2010), this awareness led young people to withhold emotional expressions, which resulted in a lack of support from the well parent. They also adopted roles to support the parent, such as providing *“comfort and support”* (Millenaar et al., 2014), and adopting roles to compensate for the affected parent. Other young people felt uncertain about how to support.

c. Siblings

Three studies focussed on the effect of having a parent with YOD on the relationship between siblings. This included two studies highlighted as good quality. Comparisons between affected parent-sibling relationships and their own relationship dyad could lead to negative feelings, including jealousy and loss.

"...my sister will have had that relationship with my mum cos she's thirty-seven, so when she was my age she will have had all that with my mum but I feel as though I've missed out." (Garbutt, 2006)

Sibling relationships could also become strained due to an unbalanced uptake of responsibilities.

"I just feel as though because I live at home it's expected that I do all these things but I don't think they appreciate how hard it is... it's as though they've gotten off scott free because they don't need to do anything" (Garbutt, 2006)

d. Family system

Nine studies (two that were rated as good quality) highlighted how families either concealed/denied changes in the affected parent, or facilitated awareness by being open about dementia. Young people found concealment difficult (Allen, Oyebode, & Allen, 2009) as it invalidated their emotional responses and impacted on their understanding of dementia (Garbutt, 2006). Conversely, openness within the family helped young people understand the difficulties being experienced as a family. Young people wish to know the diagnosis and valued honesty about symptoms *"instead of trying to hide it or downplay it"* (Nichols et al., 2013).

Some young people felt forced to provide care (Svanberg, Stott, & Spector, 2010). Financial strains were also highlighted, mostly within adolescent samples

(Allen, Oyeboode, & Allen, 2009; Gelman & Rhames, 2016). Extended families could also withdraw, or relationships were impacted by the difficulties adjusting to dementia, leaving young people feeling neglected.

“We basically had a family meeting where we said that they needed to start helping us... But, they couldn’t cope with him; it was us that mainly coped with him.” (Allen, Oyeboode, & Allen, 2009)

Negative relationships were also experienced following a young person’s decision to leave home, which furthered their isolation within the family (Hutchinson et al., 2016a).

e. Peers

Eight studies, including all good quality studies, highlighted negative changes to peer relationships, including experiencing jealousy, loss and distress as a result of comparisons with their peers’ parental relationships. Isolation was a common experience for young people across studies. Emotions such as fear, shame and embarrassment were highlighted, which led to attempts to conceal the diagnosis. Studies highlighted stigma and misattributions for the affected parent’s behaviour; for example, being told *“your mum’s weird”* (Hutchinson et al., 2016).

“What I wish today, is that everyone just had to know what dementia is. That you should grow up knowing that it is an illness. So that you do not have to be ashamed.” (Barca et al., 2014).

Young people also considered the implications of genetic risk factors and this had implications on their relationships with others, including starting a family.

3. Emotional impact of caregiving

All studies emphasised the number of negative emotions experienced by young people, including anger, embarrassment, fear, guilt, confusion, frustration and regret. One participant described it as *“an emotional rollercoaster constantly”* (Lord, 2010). Experiences of grief were recurrent throughout studies,

highlighting the ongoing nature of grief in this population. Grief can be heightened by situations such as going into care (Allen, Oyeboode, & Allen, 2009).

*“She’s kind of almost it’s like there’s two Mums
and in your head, you never quite let go of... but
you’re constantly grieving for the old Mum
because she’s sort of there but not.”* (Sikes &
Hall, 2016)

The wealth of negative emotions occurring could be overwhelming, confusing, and culturally unacceptable, such as wishing for the affected parent to die (Barca et al., 2014). Combined with the lack of space to process these emotions, some young people experienced emotional and physical burnout, and mental health difficulties (depression, poor self-esteem, stress, anxiety and hostility). Conversely, studies also highlight that young people can experience positive emotions from providing care (Nichols et al., 2013).

4. Implications for developmental stages

Thirteen studies (all that were rated as good quality) made reference to the implications that caregiving had on their development. They experienced a forced ‘maturity’; for example, describing becoming *“the man of the house... at 15/16 years old”* (Gelman & Rhames, 2016), being *“thrust out of our childhood”* (Svanberg, Stott, & Spector, 2010) or having *“missed out on being a teenager”* (Lord, 2010). For some, this was overwhelming and they avoided care roles (Allen, Oyeboode, & Allen, 2009), furthering difficulties in family relationships.

This ‘forced maturity’ hindered engagement in age-appropriate life activities, such as education (Hutchinson et al., 2016a), spending time with friends (Svanberg, Stott, & Spector, 2010), and moving out of the family home (Millenaar et al., 2014). Loss occurred at different developmental transitions (Sikes & Hall, 2016). There was pressure not to individuate from the family of origin (Lord, 2010) and regression in returning to living at home (Aslett, 2014).

*“... I have not been able to focus on myself, like
other young people do. I have not had a normal
life.”* (Barca et al., 2014)

Studies also highlighted the loss of role model, particularly for adolescents (Allen, Oyebode, & Allen, 2009). When YOD occurred post-adolescence, participants felt more able to cope with the situation because they had individuated from their families and gained security and intimacy with their own family (Garbutt, 2006). Nevertheless, for young adults with their own children, feelings of guilt about care provision could occur (Aslett, 2014). Thus, caregiving impacted young people differently depending on developmental stage.

5. Support

a. Social

Fourteen studies, including all studies rated as good quality, found that social support was beneficial for young people; however some found it difficult to find support. Young people appeared to selectively open up to people (Millenaar et al., 2014), and felt more supported if the person had experience coping with loss themselves (Aslett, 2014), some knowledge of dementia (Nichols et al., 2013), or were empathic and without this knowledge.

*“I kind of get some support from my friends
because they try to imagine what it’s like...”*
(Nichols et al., 2013)

Others wanted to “*just be normal*” (Svanberg, Stott, & Spector, 2010), engaging with friends without the focus being on their caregiving experiences and more in line with social development (Hutchinson et al., 2016b).

Three papers also referenced young people’s desire to be supported by other carers of parents with YOD. For those that had participated in such groups (Johannessen, Engedal, & Thorsen, 2015; Hutchinson et al., 2016b), finding people who had managed similar challenges increased their self-efficacy, their understanding of their situations, and they experienced feelings of relief.

*“..that other kids my age have been through
some really horrible, horrible things. But they
got through it and they came out the other side
fine.”* (Hutchinson et al., 2016b)

b. Family

Six studies (two of which were good quality) highlighted that families could become closer from being involved in planning or conducting care (Allen, Oyeboode, & Allen, 2009) or by families who facilitated more 'natural', non-caring roles, such as supporting engagement in non-caring roles (Alsett, 2013). Having knowledge of dementia aided young people to be involved (Allen, Oyeboode, & Allen, 2009). The wider family also helped if they were accepting and open about the diagnosis (Barca et al., 2014), and some siblings could draw on each other for support.

“... thank god I have my sister because we can talk about it together” (Hutchinson et al., 2016b)

Some families discussed the management of distress in the affected parent and problem-solved difficulties together, often with less focus on emotional support.

“...that's the moment when as a family we have to decide whether we discuss the fact that she couldn't do it or whether we should divert attention away from the fact that she can't do it.” (Garbutt, 2006)

However, there was also conflict with the way others managed the affected parent (Garbutt, 2006), and depending on the family's stage in adjusting to the illness, they may not be in a position to support the young person.

c. Services

Service provision was mentioned throughout studies, including two studies rated as good quality. Although there were indications that receiving support from external organisations was beneficial for the family and reduced emotional burden, provision was limited or often absent. The majority of young people in studies did not feel supported, understood or recognised by services. Despite some young people wishing for information, they were reluctant to use the healthcare system or gain support, and some families would not necessarily pass on information (Barca et al., 2014).

“...the biggest stress that I have with this is that we don’t know where to go... after it was diagnosed it was a bit anti-climactic because it was diagnosed and then we were just kind of left standing there with the diagnosis and you don’t know what to do with it.” (Hutchinson et al., 2016b)

With limited service input, young people felt increased demands on them. Support may only start following a crisis, when the young person left home.

6. Coping and adjustment

a. Coping over time

Studies that focussed on coping (including all studies rated as good quality) highlighted that young people handled situations more effectively over time (Johannessen, Engedal, & Thorsen, 2016), attempted to make the most of their situations, and adapted to their parents’ needs. They used emotion-focussed coping responses, including substances, social withdrawal, and self-harm (Allen, Oyebode, & Allen, 2009), but some recognised these as unhelpful through time (Lord, 2010) and this helped young people to access support (Hutchinson et al., 2016b). Avoidance strategies included physical acts such as leaving home, avoiding information about dementia (Millenaar et al., 2014) and the future (Aslett, 2014); however some actively searched for information to prepare for the future and for providing care (Johannessen, Engedal, & Thorsen, 2016).

Over time, some young people gained reward from interactions with their affected parent.

“...even though he may not recognize us at first, if we start to play with him, or we start cracking jokes, or we do stuff that’s familiar to him, he’ll smile and laugh a bit. And that makes it worth it.” (Nichols et al., 2013)

Being able to be physically and emotionally separate from the affected parent was also seen as positive, and helped engagement in more developmentally-appropriate roles (Allen, Oyebode, & Allen, 2009; Hutchinson et al., 2016a), and

activities (e.g. education, work, socialising). These provided stability and a sense of normalisation (Johannessen, Engedal, & Thorsen, 2015; 2016; Hutchinson et al., 2016b); however, grief continued to be present (Lord, 2010; Johnanenessen et al., 2016).

b. Growing

Young people described personal growth from their experiences, including empathy, resilience and compassion towards others. The role of carer gave young people purpose and a direction in life (Hutchinson et al., 2016b) .They engaged in meaning making from a perspective of loss to promote personal growth.

“Although losing someone is a really really hard thing, maybe in a way some good can come out of it because like for example you might appreciate things in life more. You can be more sensitive to other people in any sort of similar situation whatsoever.” (Lord, 2010)

In time, emotional stress decreased and anger was replaced by acceptance and loss from missing their parent (Johannessen, Engedal, & Thorsen, 2016).

“...if you'd caught me a year ago I would have been in a different emotional place to where I am now... I think it's just a question of time”
(Garbutt, 2006)

Discussion

The review explored the impact and experiences of caregiving and family relationships of children with a parent with a diagnosis of YOD. A qualitative synthesis of 15 studies described the key aspects of young peoples' experiences, and also evaluated the quality of this research. Six interrelated themes were identified, including: a) making sense of dementia; b) changes in relationships; c) the emotional impact of caregiving; d) implications for developmental stages; e) support; and f) coping.

Making sense of dementia

Understanding YOD was a challenge for young people, with responses to the diagnosis varying between actively making sense and avoidance. Research demonstrates how the diagnostic journey for YOD is particularly protracted (van Vliet et al., 2011; Millenaar et al., 2016), and how dementia may not be considered due the perception that it is a disease of 'old age' (Johannessen, Engedal, & Thorsen, 2016). This reflects the uncertain nature of dementia for young people and their families, and emphasises the need for support during this time.

The degree of openness or concealment within the family had implications for young peoples' adjustment and coping, with this being particularly highlighted within papers rated as good quality. These opposing response styles have also been highlighted within a systematic review into family relationships in dementia (Fontaine & Oyeboode, 2013), with concealment being replaced by minimisation and denial. This may be an attempt to protect young people; however, as they are aware of the YOD (Nichols et al., 2013), concealment becomes invalidating (Garbutt, 2006). In spousal studies, adaptation to dementia involved emotional support and open communication (Fontaine & Oyeboode, 2013), which may also be relevant for the wider family system.

Changes in relationships and support

The sense of loss for the 'real' parent, and the challenges this posed, was experienced regardless of previous parent-child relationships. This was strongly supported and prevalent within studies rated as good quality. Fontaine and

Oyebode's (2013) synthesis of family relationships in dementia also highlighted that the quality of pre-morbid and current relationships influence the experience of dementia, meaning that relationship changes are influential in *how* loss is experienced. Interestingly, maintaining a connection to the 'real' parent was helpful for some, and could be seen as part of the grieving process via creating a 'continuing bond' (Worden, 2010). This highlights the ongoing nature of grief in this population and the need to consider their relationship to the affected parent.

An interesting finding is the concern that young people have for their other parent. Aldridge and Becker (1994) found that parents were not often aware of their children's needs when they were providing care, similar to current findings, and may highlight why young people felt unable to gain support. Family relationships appeared to be challenged by the presence of YOD, and may indicate variations in individual family members' adjustments to the disease.

Comparisons of parent-child relationships with peers resulted in experiences of loss. Findings were reminiscent of those in young carer research regarding feelings of being 'different' from others, having barriers to socialising, and balancing care demands and relationships (Rose & Cohen, 2010). Commonalities also extend towards stigma, lack of understanding about carers' situations, and isolation experienced as a result (Roach et al., 2008; Rose & Cohen, 2010). Indeed, Hutchinson and colleagues' (2016a) emphasised the negative impact that social responses to dementia has on young people. Young people wish to be supported by friends (Barca et al., 2014), but can find it difficult to attain support from them. Thus finding ways to support young people and educate others may be required to overcome these support barriers.

Young people consistently highlighted the desire to be supported by other young people in their situation. Indeed, the value of peer support has been recognised (Bunn et al., 2012; 2015; Keyes et al., 2016). In a number of included studies, young people appeared to benefit from peer-support groups (Johannessen, Engedal, & Thorsen, 2015; Hutchinson et al., 2016b); however the availability of such support appears limited.

Implications for developmental stage

The developmental implications of YOD across both adolescence and adulthood, and the transitions between stages, fits with research into other young carers (Rose & Cohen, 2010) and with findings from dementia research (Dellman-Jenkins, Blankemeyer & Pinkard, 2001). Role reversals were common across studies, as was a sense of ‘forced maturity’, which placed responsibilities on young people to care and restricted their ability to engage in age-appropriate developmental tasks. Although stalling and regression of developmental stages were identified, some young people were able to continue to engage in developmentally-appropriate tasks over time, which had implications for their ability to cope and manage difficulties. Therefore, the synthesis emphasises the importance of being aware of the age and stage of a young person providing care, and their opportunities and barriers to age-appropriate activities.

Emotional impact of caregiving, coping and adjustment

Studies highlighted that negative emotions are prominent in caregiving, with implications for their level of stress and coping. This finding was pervasive irrespective of study quality. The risk of mental health difficulties as a result of unmet needs and lack of support are highlighted in the current synthesis, in the YOD literature (Millenaar et al., 2016) and in the young carer literature (Rose & Cohen, 2010). Scottish estimates of mental health difficulties amongst young carers indicate that they are twice as likely to report mental health problems as non-carers (Scottish Government, 2017). Importantly, negative emotions appeared to lessen through adjustment and coping over time (Johannessen, Engedal, & Thorsen, 2016), which fits with models of adjustment.

The experience of grief has been consistently expressed within YOD carer research (Spreadbury & Kipps, 2017). In the present review, descriptions included prolonged grief (Lord, 2010), anticipatory grief (Aslett, 2014), disenfranchised grief (Allen, Oyebode, & Allen, 2009), and dementia-specific grief (Sikes & Hall, 2016), which highlights the extended nature of grief and emphasises the need to consider grief in young people’s adjustment and coping.

Almost all studies emphasised the variety of problem- and emotion-focussed strategies that young people used to cope. It may be that avoidant, emotion-

focussed strategies were employed when a sense of helplessness and lack of control of the situation were prominent (Johannessen, Engedal, & Thorsen, 2016), whereas increasing knowledge facilitated problem-focussed coping (Millenaar et al., 2016). Increasing knowledge of dementia has been shown to increase caregiver's perceptions of coping, and reduce depression rates (Paton et al., 2004). Studies also highlighted growth resulting from adjustment and mastery of their situations, which can influence young peoples' self-efficacy (Hutchinson et al., 2016b), and lead to changes in identity development (Rose & Cohen, 2010). Thus, coping represents a complex picture and deserves some consideration in terms of individual adjustment to caregiving.

Taken as a whole, emotional challenges appear to be consistent with the stress-process model of caregiving in dementia (Pearlin et al., 1990), with changes in relationships, challenges to developmental activities due to adopted roles, problems in social support, and lack of resources appearing to influence the emotional and physical well-being of young people. The model proposes that adaptation and adjustment is influenced by stressors, resources, and situations within the caregiving experience (Pearlin et al., 1990), which appears relevant to how young people cope during this time.

Support from services and implications to services

The lack of appropriate service provision was frequently raised. Young people's reluctance to use services out of fear of the consequences for their affected parents is not unique to YOD carers (Rose & Cohen, 2010), and the notion that young people were missed by or neglected by services (Barca et al., 2014; Gelman & Rhames, 2016) highlights the need to consider how to engage young people in receiving support. This has implications for educational and occupational services as young people can feel unsupported in areas of their lives that may provide stability and meaning. Given that young people felt that YOD is not understood by many, services may need to consider systemic ways of working to fully support young people in care.

Research highlights the need for a whole family approach to support (Allen, Oyebode, & Allen, 2009; Rose & Cohen, 2010; Johannessen, Engedal, & Thorsen, 2015; Hutchinson et al., 2016a; 2016b; Gelman & Rhames, 2016), focussing on aspects of communication within relationships, information provision, and

practical support. Giving young people a voice and a chance to understand the support they require to balance caregiving and developmentally-appropriate activity would assist in addressing some of these difficulties.

Strengths, limitations and implications for future research

The strengths of the current review include the reproducible search strategy and inclusion of unpublished literature; however, as searching for qualitative literature can be influenced due to indexing issues, it may be that all available literature was not found. There were a number of limitations with the review. Included studies were conducted within Western cultures and within traditional 'nuclear families', thus restricting the generalisability of findings to other family structures.

The quality of included studies was mixed. How studies chose to present their findings influenced the scoring of quality in the present review. This was particularly seen within the published studies, with three out of the four good quality studies being unpublished theses. Issues with study presentation have been previously highlighted within qualitative research (Walsh & Downe, 2006). The presentation of participant quotations was a particular strength in all but one of the included studies. In addition, several studies explicitly stated sampling issues or limitations, which added to the transparency within this research. However, eight studies provided limited or no evidence of researcher reflexivity. Reflexivity is particularly important in assisting readers to consider findings in the context of a researcher's experience and motivations (Yardley, 2000). This has implications for the transparency of findings within these studies, and future research should aim to provide clear information on reflexivity (Berger, 2015). In addition, the wide variation in age ranges, inclusion of mixed parent-child gender dyads, differences in dementia types, and differences in living situations for both the young person and affected parent were also noted. These factors are prevalent in the YOD literature (e.g. van Vliet et al., 2010, Millenaar et al., 2016), but as there was variation in the provision of these details, the synthesis could not fully account for the influence of these factors in the findings. Future research should ensure that such factors are measured and considered when accounting for the homogeneity of samples. Some studies included participants whose affected parent had died (e.g. Lord,

2010), which may have influenced their emotional experiences; however, several studies were adolescent-specific samples, allowing for differences in age ranges to be explored. Research is needed to understand young children's experiences of having a parent with YOD. Further research is required to understand the impact of gender dyads on young people's experiences.

Conclusions

The review synthesised the experiences of young people with a parent with YOD, highlighting six interrelated themes relating to their attempts to understand YOD, the changes to family and social relationships, the emotional and developmental influences of caregiving, support, coping and adjustment to YOD. These themes appear to fit with wider research with caregivers in dementia, within existing caregiver stress models (Pearlin et al., 1990), and with literature into young carers. The synthesis adds to existing knowledge by providing an understanding of experiences specific to young people, including concerns about wider family relationships, social support and regarding personal future development. Young people are largely under-represented in support systems. Support provisions need to take into account the heterogeneity of experiences within this demographic, and develop family-wide support. Further research is required to explore younger age groups and gender-specific difficulties.

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Chapter 2: Major Research Project

Responding to Stress and Distress in Young Onset Dementia: an Interpretative Phenomenological Analysis of a Biopsychosocial Group Intervention for Carers

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Plain English Summary

Background: When an individual has dementia, family members provide essential care to support them to remain at home. This can be both challenging and rewarding. Services are developing group interventions to help support caregivers deal with the challenging and distressing situations that they face when providing this care. It is important for services to understand how these interventions work so that support can be adapted to best serve the needs of carers. There has been limited research into caregiving interventions for people with a family member with young-onset dementia (YOD). This study aimed to explore how carers experienced the “Responding to Distress in Dementia” group being offered within NHS Lanarkshire, and what influence participating in this group had on caregiving.

Methods: Five carers, who provided support to their family member with YOD, were interviewed. Interviews were recorded and analysed using Interpretative Phenomenological Analysis.

Results: Findings covered the whole ‘caregiving journey’ from first noticing symptoms, experiences in the group, and the time until interviews. Four main themes were identified about the group. ‘*Connecting to other carers*’ showed that the carers in the group developed strong relationships. ‘*Learning about caregiving*’ highlighted the knowledge about dementia, caregiving, and coping with difficulties. ‘*Group factors*’ indicated the importance of group size, effective facilitation and flexibility of group structure. These experiences resulted in the final theme, ‘*reduced carer distress*’. During the post-group period, there were three main themes. ‘*Maintaining support*’ emphasised the importance of keeping the carer community going. ‘*Applying learning*’ showed how carers used the knowledge gained from the group in their daily lives. Finally, ‘*normalising caregiving*’ highlighted the ongoing challenges of caregiving, and to recognise and respond to distress.

Conclusion: Participants described a range of experiences relevant to the study aims, and it is hoped that the findings can help services to respond to YOD carers more effectively and generate further research in this area.

Abstract

Background: Family carers are fundamental to supporting people with dementia to remain at home; however psychological distress can occur as a result of their caring role. Research into the effectiveness of interventions for caregivers of people diagnosed with Young-Onset Dementia (YOD), the experience of those using such interventions, and the mediating processes, are limited. **Methods:** Five carers, providing support for a family member with YOD, were interviewed with the aim of exploring how they experienced the “Responding to Distress in Dementia” group being offered within NHS Lanarkshire. In addition, the study aimed to identify the influence that group participation had on caregiving. Interviews covered the whole ‘caregiving journey’ from first noticing symptoms, experiences in the group, and the time until interviews, and were analysed using Interpretative Phenomenological Analysis. **Results:** Within the group experience, four superordinate themes were identified: *‘connecting to other carers’*, *‘learning about caregiving’*, *‘group factors’* and *‘reduced carer distress’*. During the post-group period, three superordinate themes were recognised: *‘maintaining support’*, *‘applying learning’*, and *‘normalising caregiving’*. **Conclusions:** The study highlighted several interrelated themes involving creating connections to carers with similar experiences, social learning, and supportive learning through group structure and facilitation. Many of the processes are found within existing dementia caregiver intervention research. Implications for service provision and future research are outlined. Research examining the effectiveness of the intervention group used is currently underway.

Keywords: Young-Onset Dementia; YOD; Stress and Distress; carer; IPA

Introduction

Around two-thirds of people with a diagnosis of dementia live at home (Livingston et al., 2014) with the support from their families. During this time, carers can experience psychological difficulties from their caring role (Scottish Government, 2010), which has implications not only for themselves but also for the person they care for. For caregivers, increased levels of burden, depression, stress, and health difficulties as a result of their caregiving role are well recognised in the literature (Brodaty & Berman, 2008). Much of the research focuses on those diagnosed after the age of 65, termed Late-Onset Dementia (LOD), with less focus on those diagnosed prior to the age of 65, known as Young-Onset Dementia (YOD).

Although younger and older caregivers can experience similar difficulties (Roach et al., 2008), there are important distinctions between these groups. Families with a parent with YOD are more likely to face financial and employment difficulties (van Vliet et al., 2010) as the onset of dementia occurs when the affected parent is of working age. Parents may be supporting dependents living at home who can find the change in relationships distressing (Roach et al., 2008; Wilson, 2017), or in the process of launching children into independence from the family, which is challenged by children taking on supporting roles (Spreadbury & Kipps, 2017). In addition, Frontotemporal Dementia (FTD) is more common in YOD (Viera et al., 2013), and people with YOD experience more severe and pervasive symptoms, including more pronounced behavioural changes (Mendez, 2006).

Much of the research in YOD focuses on understanding the experiences of those affected by dementia, including family caregivers. A recent systematic review into the experiences of people with YOD and their family members (Spreadbury & Kipps, 2017) highlighted the challenges faced by carers from their partner's initial symptom onset to post-diagnosis. Carers had difficulty identifying symptoms of dementia and attributed changes in their family member to psychosocial difficulties such as stress and depression (Ducharme et al., 2013; Wawrziczny et al., 2016). Diagnosis was often a lengthy process (van Vliet et al., 2013) with uncertainty and misdiagnosis (Mendez, 2006) contributing to distress during this time. Adjustment to diagnosis involved searching for information

about YOD (Millenaar et al., 2014), managing financial changes (van Vliet et al., 2010) and changing family roles (Harris & Keady, 2004), all whilst balancing employment and parental roles. Emotional and cognitive responses following diagnosis have been well established in the literature, including burden and strain, concerns about the future, and feelings of loss and grief (Spreadbury & Kipps, 2016; 2017). Given the number of stressors and challenges that can impact upon carers, the focus of research has started to shift towards interventions for supporting caregivers to cope with their caring roles.

Caregiver Interventions

Interventions for dementia caregivers aim to provide knowledge, understanding, and skills for facilitating the caregiving role. In the LOD literature, two meta-analyses (Brodaty, Green, & Koschera, 2003; Sörensen & Pinquart, 2006) have shown that psychosocial interventions reduce the adverse effects of caregiving; however, both studies highlighted issues within this research, such as small-to-moderate effect sizes, small sample sizes, and wide variation in group content and applied techniques. The meta-analyses supported the use of psycho-educational group interventions over other group-based support paradigms (Sörensen & Pinquart, 2006). It is, however, difficult to ascertain the effectiveness of interventions with YOD caregivers as many of the samples in LOD research combine younger and older caregiver populations (Brodaty, Green & Koschera, 2003), with YOD caregiver samples not being reviewed independently.

Although useful, quantitative studies of effectiveness in these mixed samples do not offer explanations as to the specific aspects of, or processes within, the intervention that may mediate reductions in challenging caregiving effects. This is partly due to the complexity and multi-componential constitution of interventions (Sommerlad et al., 2014). In a systematic review of UK-based interventions for non-condition-specific carers, discussing the caring role whilst it was being recognised, validated and normalised (Victor, 2009) helped facilitate positive outcomes. Other processes included the change from emotion-focussed to problem-focussed strategies (Lockeridge & Simpson, 2012), carer attitude (acceptance of the diagnosis and caring situation), access to therapists for sharing concerns, and use of cognitive reattribution techniques (Sommerlad

et al., 2014). Again, this research has primarily focussed on LOD populations and research with a specific focus on YOD caregivers is required.

Study Rationale

Ongoing research into the effectiveness of LOD caregiver interventions continues to show improvements for caregiver outcomes (Livingston et al., 2014). Due to the differences between older and younger caregivers, it cannot be assumed that interventions will be beneficial for younger carers. Further research is warranted into interventions to support the YOD caregiver population.

The present study

Within Scotland, a “Responding to Distress in Dementia” group resource was created to help carers develop an awareness of, and learn strategies for, managing their own and their affected family member’s distress (Thurlby, Cossar, & Whitnall, 2013). The seven-session group was designed to be a flexible intervention using psycho-educational and experiential components and was based on the evidence base surrounding ‘personhood’ (Kitwood, 1997) and the biopsychosocial model of distress in dementia (James, 2011). It was designed to be accessible to carers at different stages of the caregiving journey, with family members diagnosed with different types of dementia, and for both YOD and LOD. The group utilises group discussions and educational components, with an information booklet that covers the broad learning outcomes for the group. For more information on the intervention’s content, see Appendix 2.1. The group is delivered by members of the YOD service within NHS Lanarkshire and offered to carers routinely as part of their Post-Diagnostic Support. The effectiveness of the group intervention is currently being evaluated by the YOD service.

The present study was designed to explore how YOD caregivers experience the group. Of particular interest were the experiences and processes within the group that participants perceived as being influential in their caring role.

Research Questions

- What were the carers’ experiences of the group?
- What influence group participation had on their caring role?
- What processes accounted for these potential influential factors?

Methods

Design

The present study employed a qualitative approach due to the focus on exploring and making sense of experiences (Smith, 2015). Several analytical approaches were considered, covering a range of converging and diverging analytical processes and theoretical stances (Starks & Trinidad, 2007).

Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was viewed as the most appropriate method due to a number of aspects that were associated with this approach. IPA seeks to gather data from rich, reflective personal accounts from an individual's understanding and involvement in their world (Smith, Flowers, & Larkin, 2009). In addition, individuals' experiences are viewed as unique in IPA, with convergence and divergence of experiences helping to understand a particular phenomenon (Smith, 2011). Consideration is also given to the interpretative aspects of the researcher (Smith & Osborne, 2015) in understanding the participant's lived experience.

Recruitment

Participants were recruited between November 2016 and April 2017. Two forms of recruitment were used depending on whether participants were currently or had previously engaged in a 'Stress & Distress' YOD carers group. During routine nursing follow-up (as part of post-diagnostic support), previous group participants were provided with information sheets (Appendix 2.4) and gave formal consent to be contacted (Appendix 2.5) to discuss the study and arrange interviews. Prior to interview, study information was revisited and questions answered before participants provided formal consent (Appendix 2.6). For current groups, information sheets were provided at the penultimate group session. Formal consent was then taken at the following session and interview times and dates were arranged. Consent to participate was again confirmed at interview.

Study eligibility

To be eligible, participants had to (a) be a family member that provides care to the person diagnosed with YOD; (b) have completed the group within 12 months of interview involvement; (c) have attended at least four group sessions out of seven; (d) have adequate command of spoken English; and (e) be over 16 years of age.

Ethics

The study was approved by the University of Glasgow Doctorate in Clinical Psychology academic team through blinded review. Ethical approval was sought and granted by the West of Scotland Research Ethics Committee (Appendix 2.2) and site management approval was granted by NHS Lanarkshire Research and Development (Appendix 2.3).

Participants

Two carers groups were eligible for participation in the study: one active group (consisting of 10 carers) and one previous group (involving five carers). Carers from the active group were approached by the lead researcher and six initially consented to participate in the study: four participated in interviews, with two carers unavailable for interview despite attempts made by the researcher to facilitate participation (e.g. sending a letter to one carer and arranging two interviews with the other carer). Two carers from the past group remained open to nursing staff and consented to be contacted: one participated and the other withdrew before interview. A summary of the characteristics of the five participants (33% of the total potential sample) is provided below (Table 2.1).

Table 2.1 - Characteristics of interviewed carers

Pseudonym	Age	Relationship to person with YOD	Diagnosis	Estimated times		
				Diagnosis	Caregiving prior to diagnosis	Symptom onset
<i>Adele</i>	28	Daughter	Frontotemporal Dementia; Lewy Body Dementia	1 month	5 years	5-6 years
<i>Beatrice</i>	55	Wife	Alzheimer's disease	1½ years	1 year	2½ years
<i>Chris</i>	58	Husband	Alzheimer's disease	1½ years	6 months	2 years
<i>David</i>	67	Husband	Dementia NOS	1 year	9 years	10 years
<i>Edith</i>	64	Wife	Primary Progressive Aphasia	1 year	3 years	4 years

IPA requires purposeful sampling with adequate homogeneity for detailed exploration of a phenomenon. This key assumption was satisfied within the current sample as all of the carers: i) cared for an immediate family member at home, and ii) supported their family member with activities of daily living. Carers received a mixture of support from family, NHS and/or third-sector services. In addition, they had provided care for a minimum of two years and despite some being in employment, none of the carers worked full time. Four participants were spousal carers and one was a daughter. All individuals with dementia were aged 55-64 years of age and had received their diagnoses 1-20 months prior to interview. Symptom onset spanned 2-10 years.

Procedure

Interviews were conducted within NHS clinic rooms in the carer's local area. Interviews lasted an average of 66 minutes (57-80 minutes). Data was gathered using face-to-face, semi-structured interviews between the carer and the lead researcher. The interviews were supported by an interview schedule (Appendix 2.7), which was developed through consultation with members of the YOD team. In line with guidance on conducting IPA studies, this schedule was designed to be used flexibly throughout the interview (Smith, Flowers, & Larkin, 2009) so that

participant experiences could be thoroughly explored to promote rich data (Smith & Osborne, 2015).

The interviews began with a broad discussion regarding participants' experiences of dementia. Open-ended questions, with both probing and reflective questioning, were used to focus exploration of experiences. A supportive rapport was facilitated through the use of therapeutic skills such as empathic communication, validation, and summarising. Emphasis was placed on understanding the carers' experiences, allowing for elaboration of discussions, and providing the space for reflection on the influence of the group on their experience of care giving. Interviews were transcribed verbatim and anonymised prior to analysis.

Data Analysis

The IPA analysis structure provided by Smith and colleagues (2009) was used flexibly as a basis for analysis. Each transcript was analysed separately, and involved repeated listening to recordings and readings of the transcripts. Textual analysis during reading was recorded as initial notes on the transcript margins, which involved noting the contextual, linguistic, and conceptual aspects of the data (See Appendix 2.8). Following initial coding, emergent themes were developed on the adjacent transcript margin by interpretation of the meaning derived from mapping inter-relationships and differences amongst the data. These emergent themes were then organised temporally with regards to whether they referred to experiences before, during, or after the group. Lastly, themes were grouped based on the shared characteristics between emergent themes. The entire thematic dataset was combined and the process of developing common themes was repeated, generating superordinate and subordinate themes. Data 'saturation' was considered when consistent commonalities and limited additional themes emerge during the analysis (Smith, Flowers & Larkin, 2009).

Quality

Transcription accuracy was evaluated by peer review. Two transcripts were reviewed by the academic supervisor to verify the validity of the analysis (Yardley, 2000). The analytical process was also checked by both the academic

and field supervisors to assess the validity of emergent themes and the overall analysis. The lead researcher also assessed for deviancy from participant meanings by returning to the data and matching statements with the themes generated, which resulted in further changes to the analysis.

Researcher Reflexivity

The lead researcher co-facilitated the carers group in 2014, and facilitated a five-month individual therapeutic intervention using the group resources. From these experiences, the lead researcher was aware of his assumption that carers would experience burden and guilt about the challenges of caregiving, and that the group may serve as a place to relieve themselves of these. Discussions with supervisors also indicated his emphasis on psychological components within the group, which was acknowledged as a potential influence during the analysis. In addition, advice was sought following the first interview to ensure that the lead researcher was fully exploring participants' experiences. He completed a six-month placement in the YOD service, having working relationships with staff that were sometimes discussed during interviews. This experience raised concerns about the openness of participants regarding negative aspects of the group or the service, and so efforts were made to remain neutral in interviews, for example, by asking for both positive and negative experiences. Lastly, the lead researcher was familiar with the intervention material itself, which could serve as a potential interpretative 'lens' for the IPA approach (Smith & Osborn, 2015). In order to separate the lead researcher's experiences from those of the participants, his experiences were detailed in a reflective diary prior to analysis. These reflections were referred to during the analysis and in conversations with the academic supervisor to ensure transparency and differentiation between the researcher's assumptions and the participants' experiences.

Results

Interviews highlighted aspects of the whole caregiving journey, which was broadly split into sections prior to the group, during the group, and following group completion. Although the experience of the caregiving journey prior to the group emerged from the data, this was not a research question and was out-with the scope of the paper to discuss in detail. However, pre-group experiences provide context for understanding the experience of the group and post-group caregiving, and so will be presented briefly. For the other sections, seven interrelated superordinate themes, and several subordinate themes, were identified and presented in Figure 2.1. The likelihood that data saturation was reached was indicated during the analysis of transcript four, with no novel themes being generated by the analysis of a further transcript.

Participant quotations were adapted for presentation unless they augmented the flow of the extract. Removed pauses and condensed sections are highlighted by three dots (...), and colloquial terms and utterances such as “emm” were removed to enhance reading of quotations.

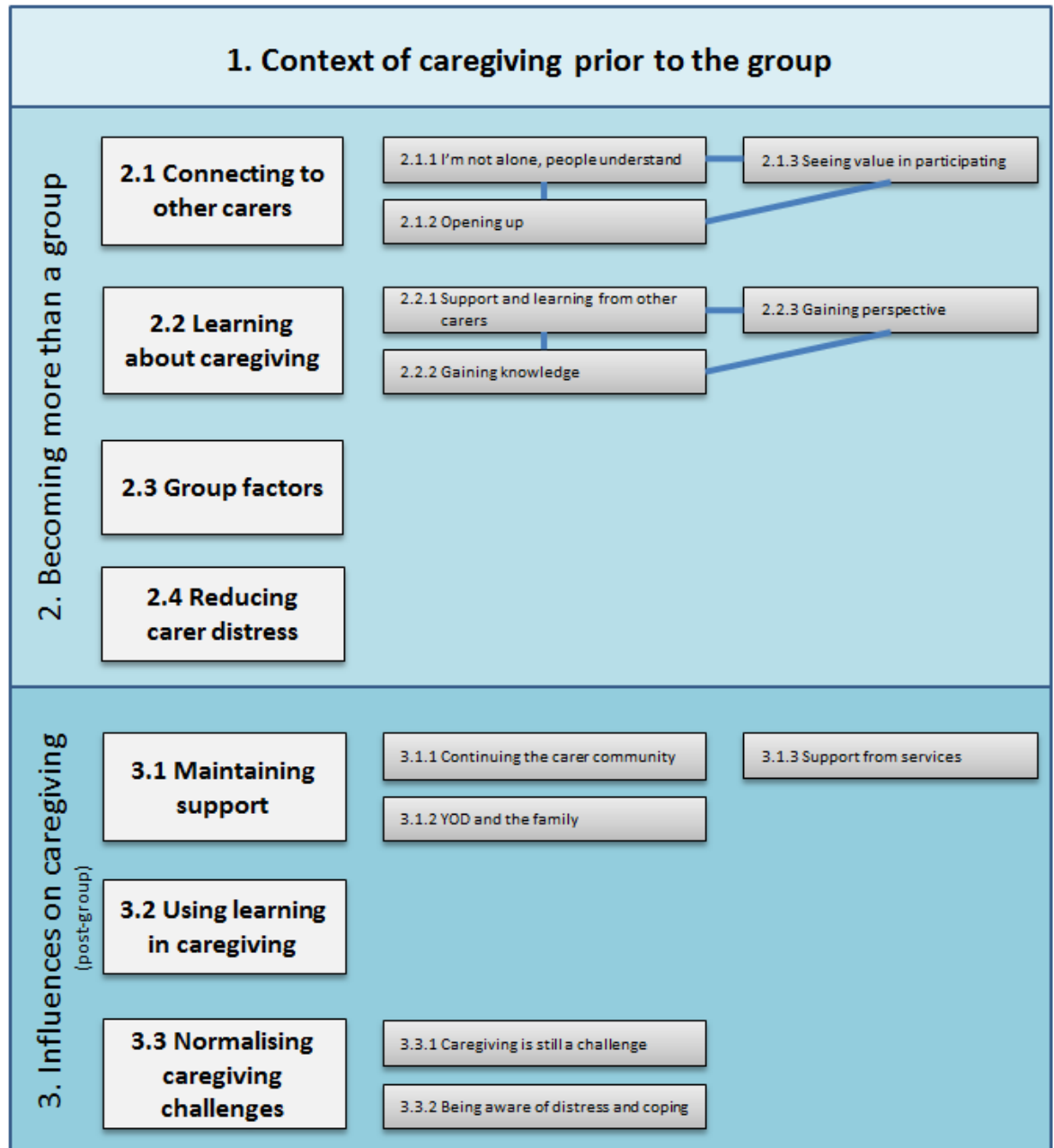


Figure 2.1 - Diagrammatic representation superordinate (**white boxes**), and subordinate themes (**grey boxes**).

1. Context: The caregiving journey prior to the group

All participants described difficulties within the diagnostic journey and post-diagnosis, which included isolation, lack of support and understanding, and caregiver distress.

Every participant described feeling alone prior to the group, knowing those that had LOD but no one with YOD. For those that had prior caregiving experiences, they described feeling deskilled when caring for their family member with YOD. Many caregivers found that friends, family and the general public did not understand YOD. For example, David found that people would avoid discussing his wife's dementia, furthering his sense of isolation. Many participants described the challenge of finding age-appropriate support from services when symptoms first presented. They also highlighted difficulties in obtaining a diagnosis, with symptoms being misattributed to stress (Chris) and depression (Edith) by GPs.

In addition, participants focussed on caregiving roles at the cost of their own self-care, and Edith remarked that "*dementia takes over everything*". Themes of loss were pervasive during this period. Many participants tried to source information; however they found this information confusing and at times distressing. Increased levels of stress and impacted on their mental health. For example, several participants described experiencing anxiety, depression, and low self-esteem. Difficulties also affected the wider family network and many participants felt reluctant or unable to ask for support from family because of their own difficulties coming to terms with YOD.

2. Exploring the group experience: Becoming more than a group

Within the experience of the group, superordinate themes reflected the processes of becoming *connected* to other caregivers and engaging in the process of *learning*, of which lead to *reduced distress*. Also noted in interviews were *factors directly related the group structure, content and facilitation*.

2.1. Connecting to other carers

Participant interviews highlighted the *importance of carers coming together in the group*. There were three subthemes: 'I'm not alone, people understand', 'opening up', and 'seeing the value in participating'.

2.1.1. I'm not alone, people understand

"with my dad being ill for so long we've had no support before, so coming to the group was

just... amazing to hear we're not alone..."

(Adele)

Every participant highlighted that they were no longer alone, and emphasised the relief and surprise at finding others in the same situation. Edith explained how *"you read in books that there's thousands of people like you"*, which contrasted the difference between 'knowing' and the physical presence of others. For Adele, being with another adult child of a parent with dementia was particularly helpful. Participants used metaphors such as being in the same *"boat"* (Beatrice), *"level"* (Chris), and *"planet"* (David) to emphasise feeling understood and being among similar carers. Also of importance was a non-judgmental, validating experience within the group:

*"... other people understand what you're saying
'cause you can just say what you feel and
nobodys' gonnae judge or... or you don't feel
stupid..." (Adele)*

2.1.2. Opening up

*"... I'd just sit and start speaking if you know
what I mean just from the heart, from the
mind..." (David)*

Both Chris and David described speaking spontaneously after identifying the commonalities in caregiving experiences. Many participants felt comfortable enough to share their situations, thoughts, feelings and more personal experiences. The 'release' of worries and emotions was often discussed in interviews, reinforcing the sense of community and normalising expectations of themselves in their caring role.

*"...they had, reached that stage of being able to
open up, and sometimes opened up and got,
quite emotional about it. It was good, because
you need that, release" (Chris)*

Openness was facilitated by carers having a space to talk about the family member with dementia alone, which rarely occurred outside of the group. There

were limitations to this openness. For example, David indicated that some of the strategies no longer worked for his wife. Regardless, David *“didn’t want to discourage anyone ”*. Thus, openness was subsumed by a desire to support the other carers.

2.1.3. Seeing value in participating

Participants spoke about how they found value in participating in the group. For example, this allowed Edith to recognise the importance of self-care:

“...listening to them... all the wee things that they would do and, and I thought ‘you know I’m gonnae enjoy this and I’m gonnae take time ’...”
(Edith)

This highlights an underlying stigma regarding self-care, which was addressed via group participation. Participants valued hearing from each other, and indicated that they had developed strong relationships with each other.

“..you develop this sorta, rapport, with... sort of good friendship going on with each other, mateyness sort of thing, and care for them also...” (David)

David also indicated the group being like a *“clan”*, and Beatrice spoke of the group being *“like meeting up with a group of pals”*. These descriptions emphasised the cohesive nature of their relationships, and the respect towards other carers, both as a person and in their caregiving experiences.

2.2. Learning about caregiving

This superordinate theme reflected the sources of learning and the impact learning had during the group. Three subthemes were generated: ‘support and learning from other carers’, ‘gaining knowledge’ and ‘gaining perspective’.

2.2.1. Support and learning from other carers

Carers provided support to each other through sharing care approaches. For example, Chris learned about breaking tasks into chunks from another carer. The

encouragement and support provided within the group was important and participants appeared to value peer learning, which included an implicit motivation to support each other.

“... it was the case of, ‘well what can I offer to help you? What can you tell me that helps me?’, and that was when the support really began to work” (Chris)

Some participants explained finding conversations difficult as they had to face the progressive nature of dementia.

“...how bad he’s gonnae get or how bad he could get... I’d say maybe in the back of ma head I knew that was going to happen I just I didn’t want tae, admit it to myself” (Beatrice)

By discussing difficult situations in the group, carers could be supported by others. Chris also experienced difficulty when discussing violent behaviour, but he recognised that information provided “*an encompassing view*” of a range of presentations.

2.2.2. Gaining knowledge

“... you need an expert to explain to you really what’s going on really... I was looking for clarity and understanding and knowledge, and I think I found some of that there” (David)

In addition to peer learning, participants learned from group information booklets and content-directed group discussions. Carers learned about symptoms of dementia and distress behaviours, could query information with facilitators and explore the group content. This allowed Adele to understand her father’s distress in response to dementia symptoms such as hallucinations, to which she found that “*it just made everything make sense*”. Beatrice had a similar experience:

"... there was something in the book... and then it happened at home, it happened with [Husband] and I thought 'oh that's alright', I think it was the... hallucinations..." (Beatrice)

Participants were able to return to the booklets after the group was finished; however, they were also aware of content that was irrelevant to their family member's dementia type.

2.2.3. Gaining perspective

Participants gained an understanding of their stage in the caregiving journey by comparisons to other carers' situations. David's use of the metaphor "*different bus stops, different routes*" highlighted both the progressive nature of dementia and the differences in dementia subtypes between carers. Perspective-taking provided a sense of relief and an opportunity to gain support with potential future difficulties. Chris identified that by sharing, "*the penny drops for you*", indicating the enhanced understanding and normalisation of their own situations through reflecting on their experiences in the group. This also occurred with beliefs about caregiving itself.

"...sometimes you feel guilty that you're not there all the time... they explained like that you can't be there all the time..." (Adele)

By discussing implicit assumptions about caregiving, participants reappraised their beliefs about their own caregiving situations. This occurred in Edith's group, where another carer's expression of commitment to self-care allowed Edith to engage in self-care and changed her beliefs about this practice being selfish. For Beatrice, this led to an awareness of her stress as she noted: "*I didn't even realise there was a load on my shoulder*".

2.3. Group factors

Some participants discussed their experience of the way the group was conducted. For example, Chris raised the importance of group size in order to facilitate everyone opening up. Edith highlighted being able to approach facilitators as helpful:

"...if you wanted to discuss anything, freely, you were, that it was okay to discuss anything you liked, but if there was something that was really bothering you, or, that was personal, you could say to the girls [facilitators] and they would take time, to, to go through that with you..." (Edith)

Having the space to discuss aspects of their difficulties that they were concerned would upset their affected family member was important to carers, further evidenced by their wishes to have disclosures within the group be acted upon by facilitators.

There appeared to be flexibility within sessions, and a balance between adhering to structured content and carer-driven conversations, with participants preferring discussion elements. Although there were mixed experiences of group facilitation, carers recognised the benefits of having structured content. Hence, the way the group is conducted and materials used remain important aspects of the group.

2.4. Reduced carer distress

For all study participants, the group was a positive experience and led to reductions in their distress. For Adele, learning strategies to support her father was helpful.

"...now we know about how-how to do things, it's taken away so much stress..." (Adele)

Adele also referred to being in the group as “*therapy*”, and other participants also indicated a reduction in their own stress levels. It is important to note that participants benefitted in different ways, and in different intensities. For example, David felt he would have benefitted from participating at an earlier stage in his caregiving journey.

“...if I'd been there, nine years ago it probably be more beneficial then but, then again it, what works for someone else doesn't necessarily work

*for you it really depends on your circumstances
really..." (David)*

3. Influences on caregiving following the group

Following completion of the group, interviews highlighted three superordinate themes reflecting the *maintenance of support*, the continued use of *learning from the group in their caregiving roles*, and *normalising caregiving*.

3.1. Maintaining support

This superordinate theme focuses on the continuation of support following the group and is comprised of three subthemes reflecting the sources of support, including from peers, their respective families and from services.

3.1.1. Continuing the caregiving community

All participants explained the importance of keeping their newfound community. Carers utilised social media to arranging meetings following the group, which Beatrice referred to as "*us time*", indicating the continuing bonds created from the group. This connection was crucial to carers, as Adele highlighted "*when you've got it you need to cling on to it*", and Chris considered the loss of connection as threatening, stating that "*it would take something away from what I'd, what I'd gained*".

For many of the participants, knowing that they were not alone was comforting and remained with them. For example, Edith reminded herself about the experience of other carers in her group, allowing her to normalise her situation and find ways to cope.

"... I think 'I wonder how [Carer]'s getting on with her husband'... then I think 'you know what, there's people just, as bad off as yourself and they're just coping with it and getting on with it, just the very same, so just, carry on and do what you're doing'..." (Edith)

3.1.2. YOD and the family

Following the group, some of the participants had found new ways to engage their family network in understanding and supporting the family member with dementia; however, this support remained mixed.

"we took all the booklets to all our family as well, let them read it... got them a bit of a better insight, we were going back and telling them all the different things we were now changing in the house, getting them to say like if any if my dad's starting to do anything "you need to let us know, this is how you document it, so's we can try and see patterns, triggers, anything that could be"... and they all started doing that so that was a big help for us..." (Adele)

Other participants also noted changes within their family, with Beatrice's son actively looking at information from the internet, and Chris' children asking to help. Thus, the group appeared to facilitate the beginnings of a whole family approach to providing care. However, spousal carers remained reluctant to ask their children for support.

3.1.3. Receiving support from services

Having access to appropriate and effective services was important to carers; however, there were mixed experiences in this regard. Some participants explained how the YOD service provided valuable support to them.

"I know [CPN]'s there if I need... to ask questions or... a wee bit of advice..." (Beatrice)

David also found a benefit from being able to offload to staff, recognising how *"just speaking to someone, does help"*. Conversely, other participants wished for more input but were reluctant to ask. Participants identified difficulties with non-specialist services following the group, such as with staff in hospitals and GP practices and their understanding of YOD.

3.2. Using learning in caregiving

Participants spoke about being able to apply learning following the group. Although participants indicated that many of challenges with caregiving remained, most were able to apply and adapt strategies learned in the group, and recognise when they were no longer suitable. For others, having an enhanced understanding of dementia helped them cope with changes in the affected family member's dementia.

*"it's funny cause I didn't panic ... I just knew...
that there was, part of the Alzheimer's because
they had mentioned it at the group and that I
wouldn't have known otherwise" (Beatrice)*

Participants used both practical and cognitive coping strategies to help them manage situations they faced. For many participants, this was in the form of discrete sayings or 'catchphrases', such as Chris learning to break things down, and Edith taking "ten steps back" and recognising that she is doing the best she can.

3.3. Normalising caregiving

This superordinate theme reflected the dichotomy between coping and facing continuing challenges in their caregiving role. Two subthemes were identified: 'caregiving is still a challenge' and 'being aware of distress and coping'.

3.3.1. Caregiving is still a challenge

Whilst discussing the period following the group, many participants spoke about how caregiving remained practically and emotionally demanding. For Chris, he felt that "everyday's a different challenge", highlighting the inconsistent nature of his experience of dementia. David experienced less improvement in his circumstances following the group.

*"...the group's helped a lot really but it hasn't
changed my situation any, in reality I still have
the same situation which's, [Wife] becoming*

more dependant... I know that and I accept that..." (David)

Several participants also spoke of experiencing significant events that had consequences on the whole family system. For example, Adele faced a difficult situation in which her father's distress became unmanageable and required hospitalisation. Thus, carers can still experience challenging and overwhelming situations that require support from services to manage.

3.3.2. Being aware of distress and coping

For many participants, they explained feeling more able to cope following the group, both with the distress expressed by their affected family member, but also within themselves.

"I think when I'm stressed, I realise quicker, now, and I try... to relax" (Beatrice)

In addition, Beatrice could also draw comfort from *"knowing that [services] are here, and everybody that was in the group"*. A commitment to self-care was also noted to be an aspect of ongoing coping.

"I mean, going, look after [Wife] depended on how I am, and being with the group I think has made me feel a bit better, so being in, the concept that 'I am better than I was' I look after her better, so, looking at it that way, yes..." (David)

Similarly, Beatrice was able to arrange the couple's week to incorporate time to herself. These were seen as positive changes, and aided by the perspective gained from speaking to other carers.

Discussion

The present study explored the experiences of carers of the “Responding to Distress in Dementia” group, aiming to identify the processes which (a) contributed to their group experience and (b) influenced caregiving following the group. Findings covered the whole ‘caregiving journey’ from first noticing symptoms to post-group experiences.

Within the group experience, four superordinate themes were identified.

‘Connecting to other carers’ highlighted the transition from social isolation to developing strong relationships to those with similar experiences. *‘Learning about caregiving’* emphasised the knowledge gained about the care experience for both the care-receiver and care-provider, leading to the development of coping strategies. *‘Group factors’* focused on specific aspects of the group that facilitated the group experience and included group size, effective facilitation and flexibility of group structure. Lastly, *‘reduced carer distress’* recognised the benefits to the participating carers and also personal characteristics that influence the effects of the group. During the post-group period, three superordinate themes were identified. *‘Maintaining support’* emphasised the continuation of practical and emotional support from peers and services, and recognises the balance engaging wider family supports. *‘Applying learning’* highlighted the carers’ continued use of strategies and understanding of dementia to help them cope. Finally, *‘normalising caregiving’* recognised the ongoing challenges of caregiving and their enhanced ability to recognise and respond to distress.

‘Connecting to other carers’ and ‘Maintaining support’

The theme *‘connecting to other carers’* was important given the challenges noted during the pre-group period, such as the lack of understanding of YOD and perceived stigma experienced by carers from society. These experiences resonate with existing evidence regarding experiences of caregiving in YOD (Spreadbury & Kipps, 2016; 2017) and fit with social model of disability research in dementia (Gilliard et al., 2005). The strong peer support network created within the group highlighted several important interpersonal processes. Namely, being understood and validated by peers and recognising the shared experiences

through opening up, which were identified as important mechanisms of change in a systematic review of caregiver interventions (Victor, 2009).

Reducing isolation is a central theme across the research with dementia caregivers (e.g. Ducharme et al., 2013). This theme proliferated discussions during interviews with all participants, despite previous involvement with dementia groups. Participants highlighted the importance of being with other YOD caregivers. Indeed, the perceived similarity between group participants had been found to be an important mechanism of change for caregiver interventions (Victor, 2009), in addition to peer support for LOD carers (Bunn et al., 2012; 2015). For participants in the present study, their commitment to continued social contact emphasised the importance of peer support. Indeed, the creation of friendships and support networks shares similarities with a systematic review of LOD psychosocial interventions for caregivers, with this social support being a key mechanism of change (Elvish et al., 2013).

‘Learning about caregiving’, ‘applying learning’ and ‘normalising caregiving’

Within the group, learning was derived from other carers and group content. Several processes were identified, including reciprocal sharing of knowledge between carers, learning about dementia, having access to specialist knowledge and information, and normalisation of their experiences. A study of a psycho-educational, LOD carer intervention highlighted similar processes (Sommerlad et al., 2014), with cognitive and behavioural coping strategies also being identified as important. Without intervention, YOD caregivers used coping strategies that led to adjustment difficulties and long-term negative outcomes (Lockeridge & Simpson, 2012). Within the present group, changes in both emotion-focussed and problem-focussed coping strategies were noted. For example, participants utilised emotional-focussed self-disclosure within the group and learned different problem-focussed strategies for their difficulties. Importantly, beliefs about self-care were addressed and they gained social permission to engage in self-care. Therefore, having the space within a group to address these with other carers facilitated changes to coping.

Within LOD literature, research has noted concerns around including people at different stages of the dementia journey in groups due to the potential for distress resulting from becoming aware of the future (Bunn et al., 2012). Although some of the participants were concerned about discussing the future, the group offered several benefits for discussing this. Benefits included being able to express emotions associated with fear and concern for the future within a supportive environment, and the opportunity to discuss such aspects with people who are experiencing similar life changing events. Thus, the processes of creating connections to carers and social learning led to changes in coping for participants. It is this interplay between the group's social aspects and structure that appear to provide the benefit recognised by carers.

'Group factors'

Group size, access to comprehensive materials for future reference, and facilitation by experienced staff were key aspects of the group. Victor's (2009) study highlighted that flexibility and personalisation of interventions were important to carers. The timing of interventions appears important with access at earlier stages of the caregiving journey being of increased benefit (Victor, 2009). In the present study, many remarked having wished to have participated sooner. Many participants experienced lengthy pre-diagnostic periods spanning years, but time from diagnosis to group participation was less, between 1 and 18 months. Thus, these remarks may be more indicative of the difficulty of diagnosing YOD, which appears to be consistently challenging within the YOD research (Spreadbury et al., 2017).

Implications, Recommendations and Future Research

Research is required regarding the effectiveness of the "Responding to Distress in Dementia" caregiver group, and to other group interventions for this population. Other recommendations include:

- Further research on group factors that facilitate effective interventions for YOD carers. Given that the present study was conducted with a small sample, a replication study would aid in generalising the findings.
- Research into long-term effects of coping strategies is also limited within YOD research (Lockeridge & Simpson, 2012), and clarification of factors

implicated in long-term coping may aid optimisation of interventions. Therefore, a longer term follow-up study would serve to provide information on the lasting benefits of the group during the caregiving journey.

- A recent systematic review has highlighted the challenges that children of a parent with YOD face and the service needs for these carers (Wilson, 2017). Further research could assess the benefits of including children of care givers in this type of group.

Findings were shared with the YOD service in Lanarkshire following the completion of the study. This discussion resulted in a change in structure to include a pre-session social component. In addition to these changes, the study highlighted further service recommendations:

- Many participants described feeling better equipped to cope following group participation. Coping was facilitated by carers being able to recognise and respond to their own stress and distress, having strategies to use for themselves and their significant others, and the development of a support network. Facilitating the development of peer support networks requires further consideration.
- Interviews highlighted variability in family support both between participants and following the intervention. Addressing the family dynamics around supporting caregiving may be an important addition to interventions, as research into the experiences of adult children recognises their desire to be involved (Barca et al., 2014). Services should take into consideration a whole-family approach to supporting a family following the diagnosis of dementia.

Strengths & Limitations

It is important to consider the strengths and limitations of the present study. The temporal structure of the interviews allowed for reflection on the caregiving journey and facilitated rich analysis; however, the short timeframe between completion of the group and interviews may not have been sufficient to allow participants to fully reflect on their group experiences.

Due to the research methods used in this study and the complexity and multi-componential constitution of group interventions, the significance of particular aspects of the group are difficult to determine (Sommerlad et al., 2014); however, processes identified in the present study have been shown to be effective in wider research.

Whilst more carers were approached to participate in the study, several declined to take part, and other carers were unable to be interviewed as they were no longer open to the YOD service. This has implications for the findings of the study as the sample may not have adequately reflected the views of those that experienced less benefit from the intervention. Previous research has also identified similar participant bias (Victor, 2009). Despite these concerns, many participants expressed negative experiences within the group.

IPA aims to analyse data from a homogenous sample. As previously noted, one daughter carer and another carer participating in a separate group were included in the sample. Despite the variation within the sample, the analysis of pre-group experiences identified important similarities between all participants, and the use of structured content within sessions was sufficient for interpretation using IPA (Smith, Flowers & Larkin, 2009). Lastly, as there were consistent commonalities and limited additional themes being identified during analysis, the likelihood of data ‘saturation’ is a relative strength in the present study.

Conclusions

The present study explored the “Responding to Distress in Dementia” group intervention for caregivers of family members with a diagnosis of YOD. It identified processes that contributed to both the experience in the group and caregiving following group completion. The study identified the interrelated themes of creating a connection to people with similar experiences, engaging in social learning, and being supported to do so through the structure and facilitation of the group. Processes within these themes facilitated positive and negative group effects. Many of these processes were found within existing

literature into LOD caregiver interventions. Based on the findings, several recommendations to service provision and future research were identified. With YOD interventions in their primacy, more research is currently needed to demonstrate effective practices and explore caregivers' experiences of using interventions.

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Appendix 0.0: Manuscript Submission Guidelines

Dementia

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Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

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11. Further information

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Appendix 1.1: Walsh & Downe (2006) Quality Framework

Stages	Essential Criteria	Specific Prompts	Scoring Criteria: 3 - Fully Met 2 - Most Aspects Met 1 - Some aspects Met 0 - None Met
Scope and Purpose			
Clear statement of, and rationale for, research question/aims/purposes		Clarity of focus demonstrated	
		Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing	
		Link between research and existing knowledge demonstrated	
Study thoroughly contextualized by existing literature		Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both	
Design			
Method/design apparent, and consistent with research intent		Rationale given for use of qualitative design	
		Discussion of epistemological/ontological grounding	
		Rationale explored for specific qualitative method	
		Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims	
		Setting appropriate	
Data collection strategy apparent and appropriate		Were data collection methods appropriate for type of data required and for specific qualitative method?	
		Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?	
		Was triangulation of data sources used if appropriate?	
Sampling Strategy			
Sample and sampling method appropriate		Selection criteria detailed, and description of how sampling was undertaken	
		Justification for sampling strategy given	
		Thickness of description likely to be achieved from sampling	
		Any disparity between planned and actual sample explained	
Analysis			
Analytic approach appropriate		Approach made explicit	
		Was it appropriate for the qualitative method chosen?	
		Was data managed by software package or by hand and why?	
		Discussion of how coding systems/conceptual frameworks evolved	
		How was context of data retained during analysis	
		Evidence that the subjective meanings of participants were portrayed (quotes?)	
		Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance	
		Did research participants have any involvement in analysis	
		Evidence provided that data reached saturation or discussion/rationale if it did not	
		Evidence that deviant data was sought, or discussion/rationale if it was not	
Interpretation			
Context described and taken account of interpretation		Description of social/physical and interpersonal contexts of data collection	
		Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena	
Clear audit trail given		Sufficient discussion of research processes such that others can follow 'decision trail'	

Data used to support interpretation	<i>Extensive use of field notes entries/verbatim interview quotes in discussion of findings</i>
	<i>Clear exposition of how interpretation led to conclusions</i>
Reflexivity	
Researcher reflexivity demonstrated	<i>Discussion of relationship between researcher and participants during fieldwork</i>
	<i>Demonstration of researcher's influence on stages of research process</i>
	<i>Evidence of self-awareness/insight</i>
	<i>Documentation of effects of the research on researcher</i>
	<i>Evidence of how problems/complications met were dealt with</i>
Ethical Dimensions	
Demonstration of sensitivity to ethical concerns	<i>Ethical committee approval granted</i>
	<i>Clear commitment to integrity, honesty, transparency equality and mutual respect in relationships with participants</i>
	<i>Evidence of fair dealing with all research participants</i>
	<i>Recording of dilemmas met and how resolved in relation to ethical issues</i>
	<i>Documentation of how autonomy, consent, confidentiality, anonymity were managed</i>
Relevance and Transferability	
Relevance and transferability evident	<i>Sufficient evidence for typicality specificity to be assessed</i>
	<i>Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</i>
	<i>Discussion of how explanatory propositions/emergent theory may fit other contexts</i>
	<i>Limitations/weaknesses of study clearly outlined</i>
	<i>Clearly resonates with other knowledge and experience</i>
	<i>Results/conclusions obviously supported by evidence</i>
	<i>Interpretation plausible and 'makes sense'</i>
	<i>Provides new insights and increases understanding</i>
	<i>Significance for current policy and practice outlined</i>
	<i>Assessment of value/empowerment for participants</i>
	<i>Outlines further directions for investigation</i>
	<i>Comment on whether aims/purposes of research were achieved</i>

Appendix 1.2: Description of Meta-Ethnography Process

Stages (Noblit & Hare, 1988)	Prompts from guidance papers (Atkins et al., 2008; Toye et al., 2014)
1. <i>Topic selection</i>	Generate the research question, and consider the appropriateness of the question to a qualitative synthesis
2. <i>Finding and selecting relevant studies</i>	Identify the focus of the synthesis Search for studies of interest, considering inclusion/exclusion criteria Determine the quality of included studies
3. <i>Becoming familiar with studies</i>	Repeated reading of included studies, familiarise with content Begin to extract concepts/themes
4. <i>Determining the relationships between studies</i>	Create a grid of concepts/themes across papers Determine how themes are related (e.g. similarities/differences) Order/merge concepts and themes into relevant categories
5. <i>Translating studies</i>	Compare papers in a sequential manner, generating translated themes
6. <i>Translation synthesis</i>	Generate synthesis via considering similarities/differences in translated themes, creating a 'line of argument' synthesis
7. <i>Expressing the synthesis</i>	

Appendix 1.3: Quality ratings per study

Papers Criteria	Davies et al. (2000)	Garbutt (2006)	Allen, Oyebode & Allen (2009)	Lord (2010)	Svanberg et al. (2010)	Nichols et al. (2013)	Aslett (2014)	Barca et al. (2014)
Clear statement of, and rationale	3	3	3	3	3	2	3	2
Contextualised by existing literature	2	3	3	3	3	2	3	3
Method/design apparent & consistent with research intent	2	3	3	3	2	1	3	2
Data collection strategy apparent and appropriate	3	2	2	3	3	3	2	1
Sample/sampling method appropriate	2	3	2	2	2	1	2	2
Analytical approach appropriate	1	2	2	2	2	2	2	2
Context described in interpretation	1	3	3	3	2	1	2	2
Clear audit trail given	1	3	1	3	3	2	3	3
Data used to support interpretation	0	3	3	3	3	3	3	3
Researcher reflexivity demonstrated	0	2	2	3	0	2	2	0
Sensitivity to ethical concerns	0	3	2	2	2	1	3	1
Relevance and transferability evident	2	2	2	3	2	2	2	2
Score	17	32	28	33	27	22	30	23
Percentage	47.2%	88.9%	77.8%	91.7%	75%	61.1%	83.3%	63.9%

Papers Criteria	Millenaar et al. (2014)	Gelman & Rhames (2016)	Sikes & Hall (2016)	Johannessen, Engedal, & Thorsen (2015) (2016)		Hutchinson et al. (2016a) (2016b)	
Clear statement of, and rationale	3	3	2	3	3	3	2
Contextualised by existing literature	3	3	2	2	2	2	2
Method/design apparent & consistent with research intent	2	3	3	2	3	1	1
Data collection strategy apparent and appropriate	2	2	2	2	2	3	3
Sample/sampling method appropriate	2	1	2	2	2	1	1
Analytical approach appropriate	2	2	1	2	2	2	2
Context described in interpretation	1	2	1	2	2	2	2
Clear audit trail given	2	3	0	3	3	1	1
Data used to support interpretation	3	3	2	3	3	3	3
Researcher reflexivity demonstrated	1	1	2	1	1	1	2
Sensitivity to ethical concerns	1	2	2	1	1	2	2
Relevance and transferability evident	2	2	2	2	2	2	2
Score	24	27	21	25	26	23	23
Percentage	66.67%	75%	58.3%	69.4%	72.2%	63.9%	63.9%

Appendix 1.4: Details of Quality Ratings of Included Studies

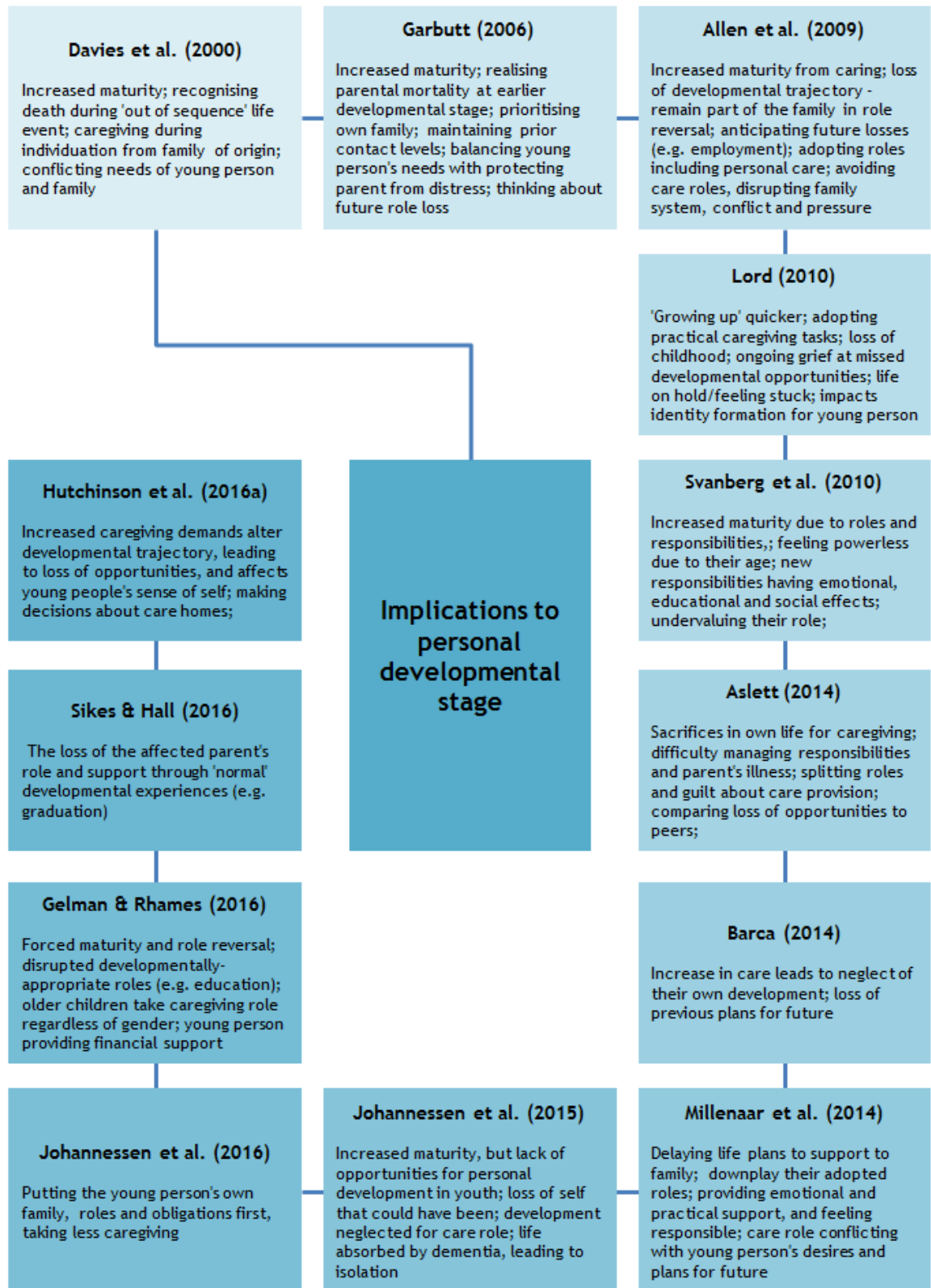
Clear statement of, and rationale for, research question/aims/purposes	All studies scored above “mostly met” for this criterion, with 11 papers meeting all prompts. Clarity of focus was demonstrated for many studies, with explicit purpose stated clearly in all. The main weakness for included studies was the clarity of focus, whereby the introductions did not clearly lead to the purpose of the study (Nichols et al., 2013; Barca et al., 2014).
Study thoroughly contextualised by existing literature	All studies scored above “mostly met” for this criterion, with seven studies meeting all prompts. Several papers (Davies et al., 2000; Svanberg, Stott, & Spector, 2010; Nichols et al., 2013; Millenaar et al., 2014; Johannessen, Engedal, & Thorsen, 2015) provided brief introductions but attempted to cover a range of research areas relevant to the topic. No studies conducted a systematic review of the literature.
Method/design apparent consistent with research intent	Studies varied in research methods, designs and the depth of descriptions provided. Two studies (Davies et al., 2000; Nichols et al., 2013) provided no rationale for use of qualitative design, and Hutchinson and colleagues’ (2016a; 2016b) papers explain their theoretical perspective without specific details into the rationale of this decision. Three studies (Nichols et al., 2013; Hutchinson et al., 2016a; 2016b) provided no details of the reason for selecting their qualitative approach, with other papers providing sufficient detail, and the three theses providing a high level of detail. All studies appeared to be conducted in appropriate settings.
Data collection strategy apparent and appropriate	All studies scored above “mostly met” for this criterion, with six papers meeting all prompts. All data collection methods were well explained. Most used methods that maximised capturing experiences; with all but one study (Nichols et al., 2013) using a semi-structured interview. One study (Sikes & Hall, 2016) used a longitudinal study design, whereas the rest were cross-sectional studies. Two studies explained having problems with data collection. In Sikes and Hall’s (2016) study, a dictation device stopped working and so notes were taken. Most studies used an interview guide except Sikes and Hall (2016), which was in line with the narrative approach taken. Most studies were face-to-face interviews, with Nichols and colleagues (2013) choosing an online format. One study provided no details (Davies et al., 2000).
Sample/sampling method appropriate	Several studies (Allen, Oyeboode, & Allen, 2009; Lord, 2010; Nichols et al., 2013; Millenaar et al., 2014; Gelman & Rhames, 2016) used participants from within the same families, although other studies did not specifically detail this. Three studies used the same sample (Allen, Oyeboode, & Allen, 2009; with Lord, 2010; Hutchinson et al., 2016a; with 2016b; Johannessen, Engedal, & Thorsen, 2015; with 2016) In Nichols and colleagues’ (2013) study, the primary author’s children were in the sample, which represents a potential bias to analysis. Eleven studies used various sampling strategies. The remaining four (Aslett, 2014; Sikes & Hall, 2016; Hutchinson et al., 2016a; 2016b) used a single approach or did not provide sufficient details of sampling strategy. However, most studies provided sufficient information to identify the appropriateness of the sampling method.

Analytical approach appropriate	Studies varied in the level of information they provided about the analytical approach, with unpublished theses providing the greatest depth and rationale. All studies made explicit reference to analytical approach, in sufficient detail. Only two studies (Nichols et al., 2013; Millenaar et al., 2014) provided details of data management usage, with two studies (Hutchinson et al., 2016a; 2016b) providing limited details on their usage of computer software. Only a few studies made explicit reference to how data context was retained; studies used participant quotations to convey meanings, with the exception of Davies and colleagues' (2000) paper. Eleven studies explained using more than one researcher for analysis, whilst four studies (Davies et al., 2000; Svanberg, Stott, & Spector, 2010; Nichols et al., 2013; Aslett, 2014; Sikes & Hall, 2016) did not explain. One study (Svanberg, Stott, & Spector, 2010) highlighted participant involvement in analysis via member checking; however this was not completed by any other study.
Context described and taken account of in interpretation	Twelve studies scored above "mostly met" for this criterion, with three studies (Garbutt, 2006; Allen, Oyeboode, & Allen, 2009; Lord, 2010) fully meeting this criterion. Although most studies described some of the social and interpersonal contexts of data collection, the stance taken by the researcher was not sufficiently explained in two studies (Davies et al., 2000; Millenaar et al., 2014). Only one study (Sikes & Hall, 2016) provided insufficient detail of interrogation of the data.
Clear audit trail given	Research processes were fully detailed by five studies, of which three were the unpublished theses and the other two were by Johannessen and colleagues (2015; 2016). As Sikes and Hall (2016) used a narrative approach, the lack of interview schedule limits reproducibility of the study, but they remained transparent about this issue.
Data used to support interpretation	All but two studies provided sufficient data to support their interpretations. Although Sikes and Hall (2016) used one quotation per theme, they provided sufficient detail to show how their conclusions were drawn from this data. Davies and colleagues (2000) provided limited quotations. The remaining studies clearly conveyed the production of their conclusions from the data.
Researcher reflexivity demonstrated	This criterion was a weakness in most of the studies. Reflexivity was sufficiently detailed in seven studies, of which three were the unpublished theses (Garbutt, 2006; Allen, Oyeboode, & Allen, 2009; Lord, 2010; Aslett, 2014; Sikes & Hall, 2016). Although not a requirement of all analytical approaches, many studies made some attempt to provide details of their reflexivity. Few studies made reference to the effects of the research on the authors and how complications were dealt with. In Nichols and colleagues' (2013) study, they highlight that the author's children are in the sample, and details removing potentially biased information from transcripts; however this does not fully reduce the possibility of interpretation bias.
Demonstration of sensitivity to ethical concerns	Two studies met all aspects of this criterion, which were the unpublished theses (Garbutt, 2006; Lord, 2010). The remaining studies varied in the level of detail provided, and this was a weakness in the research area. Four studies did not mention ethical approval (Davies et al., 2000; Nichols et al., 2013; Millenaar et al., 2014; Gelman & Rhames, 2016), with other studies providing sufficient details. Several studies varied in detailing their commitments to ethical practice with their participants, including respect, fairness, consent and confidentiality.
Relevance and transferability evident	All studies scored "mostly met" for this criterion, with considerable variation in how studies performed. At least twelve studies considered their findings in the context of other theories and research, with many comparing their findings with other studies included in the literature review. They also highlighted service and practice-related implications and explored the limitations of their studies. Conclusions in most studies were supported by evidence, with the exception of Davies and colleagues' (2000) final theme, <i>integration stage</i> , as this was not supported by participants' disclosures.

Appendix 1.5: Table of Identified Themes by Study (ticked)

Theme	Papers															n
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	
1. Making sense of dementia		✓	✓	✓		✓	✓			✓			✓			8
2. Changes in relationships following diagnosis																
a. Affected parent	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	15
b. Other parent	✓	✓	✓	✓		✓	✓	✓	✓							8
c. Siblings		✓	✓												✓	3
d. Family system	✓						✓					✓		✓	✓	9
e. Peers		✓	✓	✓		✓	✓					✓		✓	✓	8
3. The emotional impact of caregiving	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		14
4. Implications for developmental stages	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓		13
5. Support																
a. Social		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	14
b. Family		✓	✓		✓		✓		✓						✓	6
c. Services			✓		✓	✓	✓	✓	✓	✓		✓		✓	✓	10
6. Coping and adjustment																
a. Coping over time	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	14
b. Growing				✓	✓		✓		✓		✓	✓			✓	7
Papers: 1. Davies et al. (2000); 2. Garbutt (2006); 3. Allen, Oyeboode, & Allen (2009); 4. Lord (2010); 5. Svanberg et al. (2010); 6. Aslett (2013); 7. Nichols et al. (2013); 8. Barca et al. (2014); 9. Millenaar et al. (2014); 10. Johannessen, Engedal, & Thorsen (2015); 11. Johannessen, Engedal, & Thorsen (2016); 12. Gelman & Rhames (2016); 13. Sikes & Hall, 2016; 14. Hutchinson et al. (2016a); 15. Hutchinson et al. (2016b)																

Appendix 1.6: Example of Theme Generation from Included Studies



Appendix 2.1: “Responding to Distress in Dementia” Group Details

The group aims to provide carers with information on responding to distress in the person with dementia, to share ideas to help them cope with their own stress as a result of caregiving, and to reflect on these discussions with other carers looking after a family member with dementia. All carers are offered a place in the group as part of routine Post-Diagnostic Support, based on the evidence from previous studies regarding caregiver distress and strain (see Chapter Two Introduction).

Each session is conducted for up to 90 minutes, and carers are expected to read relevant sections of the information booklet in-between sessions to facilitate group discussions. Sessions begin with an agenda for the current session and an overview of the previous session, with a presentation of information from the relevant homework chapter of the resource booklet being interspersed through discussions about information presented and carer-led discussions. In some sessions, skills are provided and carers are tasked with practicing these skills and reflecting on them in the following session. The sessions end with a summary of the discussion and content, followed by homework (reading a chapter and practicing skills). Outcome measures are taken at the start and end of the group.

	Content
1	Introductions and explanation of group aims. Defining stress and distress in dementia, how it presents in the person with dementia, and introduces a decision tree regarding responding to distress. Indicating when to seek support based on the presentation of distress in the person with dementia and the carer Homework: reading section one of the resource booklet.
2	Explaining the causes of stress and distress in the person with dementia, using the biopsychosocial model. Reflection on the understanding of stress on distress. Homework: reading section four of the resource booklet; completing non-negotiables and positive qualities/skills/attributes exercises; completing guilt questionnaire.
3	Focus on carer distress and burnout, with group exercise to identify warning signs. Discussion about non-negotiables, recognising strengths of the carer, and exploring carer guilt. Homework: reading section two of the resource booklet; completing pleasant events schedule.
4	Discussion about communication and the DANCE acronym. Exploring maintaining independence for the person with dementia, the pleasant events schedule, and changing the environment. Homework: reading section three of the resource booklet.
5	Discussing medical factors behind stress and distress, medication, and accessing support. Homework: reading section five of the resource booklet.
6	Discussing coping strategies and recognising caring challenges. Detailing coping strategies and creating a caregiving ‘constitution’. Homework: practicing coping strategies
7	Reviewing the group content and following up questions. Practicing coping strategies.

Appendix 2.2: Research Ethics Approval



Office for Research Ethics Committees Northern Ireland (ORECNI)

Customer Care & Performance Directorate

Lissue Industrial Estate West
Rathdown Walk
Moira Road
Lisburn
BT28 2RF
Tel: 028 95361400
www.orecni.hscni.net

HSC REC A

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

22 August 2016

Dr Susan Turnbull
University Teacher
University of Glasgow
Institute of Health and Wellbeing, Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Dear Dr Turnbull

Study title: Responding to Stress and Distress in Early Onset Dementia: an Interpretative Phenomenological Analysis of a Biopsychosocial Group Intervention for Carers.
REC reference: 16/NI/0182
IRAS project ID: 204630

Thank you for your letter of 18 August 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs

Providing Support to Health and Social Care

Katrina Greer, prs@hscni.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to **confirm a favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview schedules or topic guides for participants [Proposed Interview Schedule]	2.3	17 August 2016
IRAS Checklist XML [Checklist_09082016]		09 August 2016
IRAS Checklist XML [Checklist_18082016]		18 August 2016
Other [Proceed to Ethics Letter - University of Glasgow]		
Other [University of Glasgow Research Health & Safety Form]		
Other [University of Glasgow Research Costs Form]		
Other [University of Glasgow Research Health & Safety Form]		
Other [Cover Letter - Amendments to Application for Research]		17 August 2016
Participant consent form [Participant Consent Form (v 2.3)]	2.3	10 April 2016
Participant consent form [Participant Consent to Contact Form (v 2.3)]	2.3	10 April 2016
Participant information sheet (PIS) [Participant Information Sheet]	2.4	17 August 2016
REC Application Form [REC_Form_09082016]		09 August 2016
REC Application Form [REC_Form_18082016]		18 August 2016
Research protocol or project proposal [Major Research Project Proposal]	5.2	17 August 2016
Summary CV for Chief Investigator (CI) [CV - Chief Investigator (Dr Sue Turnbull)]	1	29 July 2016
Summary CV for student [CV - Principal Investigator (Student - Craig Wilson)]		
Summary CV for supervisor (student research) [CV - Academic Supervisor (Dr Sue Turnbull)]	1	29 July 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- ☐ Notifying substantial amendments
- ☐ Adding new sites and investigators
- ☐ Notification of serious breaches of the protocol
- ☐ Progress and safety reports
- ☐ Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research

Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/NI/0182

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Kathrina Greer

pp:
Dr Alastair Walker
Vice Chair

Email: prs@hscni.net

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Mr Raymond Hamill
Ms Lorraine Quinn*

Appendix 2.3: NHS Research and Development Approval



Dr Susan Turnbull
University Teacher
University of Glasgow
Institute of Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow. G12 0XH

R&D Department
Corporate Services Building
Monklands Hospital
Monks court Avenue
AIRDRIE
ML6 0JS

Date 07.09.2016
Enquiries to Lorraine Quinn,
R&D Facilitator
Direct Line 01236 712445
Email lorraine.quinn@lanarkshire.scot.nhs.uk

Dear Dr Turnbull

Project title: Responding to Stress and Distress in Early Onset Dementia: an Interpretative Phenomenological Analysis of a Biopsychosocial Group Intervention for Carers.
R&D ID: L16037

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Mr Craig Wilson	Trainee Clinical Psychologist	Principal Investigator	Young-Onset Dementia Service, Glendoe Building, Coathill Hospital

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.cso.scot.nhs.uk/> or the Research & Development Intranet site: <http://firstport2/staff-support/research-and-development/default.aspx>
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research &



Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Raymond Hamill', with a stylized flourish at the end.

Raymond Hamill – Corporate R&D Manager

CC.

NAME	TITLE	CONTACT ADDRESS	ROLE
Mr Craig Wilson	Trainee Clinical Psychologist	Coathill Hospital	Principal Investigator
Dr Lisa Gadon	Clinical Psychologist	NHS Lanarkshire	Named Contact
Dr Clive Ferenbach	Clinical Psychologist	NHS Lanarkshire	Named Contact

Appendix 2.4: Participant Interview Sheet

Carers' Group: Stress & Distress for Dementia

A study of your views of caring following the group.

My Name is Craig Wilson and I am a Trainee Clinical Psychologist at the University of Glasgow and employed by NHS Lanarkshire. I would like to invite you to take part in a voluntary research study. This sheet provides you with information to help you decide if you would like to be involved in the study. Please take your time to read this information carefully. If there is anything that is unclear or if you would like to ask questions, please feel free to contact me using the details at the end of this document.

What is the purpose of the study?

Carers groups are often evaluated to make sure that they are useful, helpful, and meaningful to those who attend. More research has been conducted with older carers with family members diagnosed with a dementia after the age of 65. However, research into how groups work for carers of family members with a diagnosis of Young-Onset Dementia is limited. This study aims to find out what works in a group setting for younger carers.

Why have I been asked to participate in this study?

You have been invited to participate because:

- you are a carer for a family member with a diagnosis of a Young-Onset Dementia
- you are, or have been, in contact with the Young-Onset Dementia Service within NHS Lanarkshire
- you have participated in the "Stress And Distress for Dementia" carers group

Do I have to be involved in this study?

The short answer – no. Participation in this study is entirely voluntary. It is up to you to decide whether you want to take part. If you decide not to participate in the study this will not affect your care and treatment, nor the care and treatment of the person you care for in any way. You will still be invited to and have access to the carers group if you have not already participated in it.

What is involved?

You will be invited to meet with the researcher, at the same location as the group had taken place, to take part in a one-to-one interview. The interview will last around 30 minutes to an hour. In this time, the researcher will ask you a number of questions about how you found the group, what you found helpful and useful, what you didn't find helpful,

and what has caring for your family member with dementia after the group. There are no right or wrong answers, and the more open you are in your opinions, the better.

Is the interview recorded?

The interview is recorded onto an encrypted dictation device (so that it is safe and secure). It will be listened to by the research team for the purposes of transcription (writing down exactly who said what and when). The transcription will be completed by myself.

How will you avoid mistakes being made when you write up the audio?

Because we have to transcribe the audio, it will have to be checked for accuracy. This means that someone will be asked to listen to a section of some of recorded interviews. They will check that the research team have written down what was said correctly. They only need to check a sample of interviews, so your interview may not get checked. The person who will verify the accuracy of transcription (reviewer) will be another Trainee Clinical Psychologist who will have not met you or your relative.

What type of data are we after?

During the study, we are interested in what 'themes' come from what you discuss. We get these themes by listening to your views about the topics described above, in particular what you say and how they relate to other people's experiences. It is the themes that we find that we will use in our write up. Also, before the interview we will ask you for some demographic information (e.g. age, gender, and so forth) to give us a sense of who is taking part in the study.

Will your work be checked again?

To make sure that the themes that come from the interview analysis are correct, they will be checked much like the transcription accuracy check described above. Members of the research team and possibly another Trainee Clinical Psychologist will be given samples of transcripts and the information that I have pulled from it. They will rate how much they agree with the way I have analysed the information to make sure it reflects the information gathered from the interviews. They only need to check a sample of interviews, so your interview may not get checked.

What about confidentiality?

All study data will be transferred and stored securely and held in accordance with the Data Protection Act (1998), the University of Glasgow and NHS Lanarkshire policies, which are designed to ensure that your information is kept safe and secure. This means that your personal information will be kept completely confidential and your data will be identified by an anonymous code (for example, a different name) known only to the researcher. The

audio files will be moved onto an encrypted laptop, or onto the University or NHS server, after the interview and deleted from the dictation device. During the transcription accuracy checks, the reviewer will only have access to the audio file and samples of the transcript. For the theme check, they will only have access to the sample transcription. Your right to confidentiality will only be set aside if there is evidence that you or someone else is at clear risk of harm. If this is the case, another professional may be contacted to ensure safety. If there is any need to breach confidentiality, every effort would be made to discuss this with you beforehand.

So will I be identifiable?

Once the interview is complete and your interview is transcribed, your name will be removed. This means that you will be as anonymous as reasonably possible.

What will the results look like?

The results will be an analysis and discussion about what you and others have said. They will also be about what this means about the group experience and your role as a caregiver following the group. In some cases it will be necessary to provide a quote from yourself or others taking part to show that what theme has been found is what was said. In this case, the quote would be presented without any personal information (e.g. your name) linked to it.

What happens to the results?

I can provide you with a summary of the results of the study if you wish to see this information. This research will form part of my doctoral thesis for my training as a Clinical Psychologist. It is hoped that the results will be published in a scientific journal and may be presented at conferences. The demographic information will be presented in a table and used within publications arising from the study. Your personal information will remain anonymous within the limits of what has been detailed above.

What will happen to the interview recordings and transcripts?

The study will work within the University of Glasgow's Code of Good Practice in Research (www.gla.ac.uk/media/media_227599_en.pdf), and within NHS Lanarkshire's Research & Development guidance. This means that once the audio files have been transcribed and checked for accuracy, they will be deleted. The University will store transcripts securely for a period of around 10 years. This is standard practice and can only be accessed with a reason for doing so. Transcripts will be anonymised as explained above.

How do I withdraw from this study?

If you decide to take part and then change your mind, you can withdraw from the study without giving a reason. You can do so up until the study has been submitted to the University of Glasgow. If you do decide to withdraw, you can choose to: (a) Have your interviews and transcripts removed, but allow us to use the themes (the data which will be completely anonymous) that we found from your interview; or (b) remove all of your information from the study. If you do decide to take part, you will be asked to sign a “consent form” to show that you understand what is involved and that you freely choose to take part.

Who will know I am taking part?

I will inform the person who told you about the study that you are taking part and provide them with a copy of your consent form for your file. No other information will be shared with the young onset dementia team.

What are the possible benefits of taking part?

Taking part in the study will help us understand what makes this group useful to you and others in a similar position. It will also help us identify key elements that could be improved. This will inform other carers groups to make sure that others can benefit from the support offered. For you, it is an opportunity to share your unique experiences with services and with people who may provide care for a family member in the future.

Are there any risks of taking part?

We have not identified any significant risks involved in this study, and we do not anticipate that it will cause you distress or harm. However, there is the possibility that some questions or topics discussed may have the potential to cause upset (for example, if it reminds you of a distressing experience). If you feel distressed, you will be given time to discuss it freely and advised to speak to a member of the health service – that may be a member of the Young Onset Dementia service if they are still involved, or your General Practitioner.

Who has reviewed the study?

It has been reviewed by the following: the University of Glasgow Doctorate in Clinical Psychology academic team, the NHS Lanarkshire Clinical Quality Group, an NHS Research Ethics Committee (N-REC), and NHS Lanarkshire Research & Development.

Can I find out more information about research?

Yes. If you would like to find out about what research means in the NHS, and your rights as a participant, you can find this out on <http://www.nhsinform.co.uk/rights/>. If you want

more information about this study or wish to speak to someone about any concerns, you should contact the Chief Investigator in the first instance.

What do I do if there is a problem?

If you are unhappy or concerned with any aspect of the study then please let me know and I will do my best to address your concerns. You can also speak to any member of the research team, the Young Onset Dementia team, a relative or friend, or with your General Practitioner. If you remain unsatisfied with this response wish to make a formal complaint about any part of the care provided by NHS Lanarkshire, including care provided to you as a participant in a research project, you can contact your local NHS Lanarkshire Complaints Officer. Their contact details, and full information on our complaints procedure, are available on the NHS Lanarkshire website (<http://www.nhslanarkshire.org.uk/ContactUs/Pages/default.aspx>). You can also use the NHS Complaints Procedure Helpline (0800 22 44 88).

Do you have any further questions?

If you would like further information about this research project, you can ask me or one of my supervisors: Dr Lisa Gadon or Dr Sue Turnbull (contact details are listed below). You can keep this information sheet and if you agree to take part you will be given a copy of the signed consent form.

Thank you very much for taking the time to read this.

Yours sincerely,

Craig Wilson
Trainee Clinical Psychologist

Craig Wilson
Chief Investigator
Trainee Clinical Psychologist
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Appendix 2.5: Participant Consent to Contact Form

Title of Study: Responding to Stress and Distress in Early Onset Dementia: an Interpretative Phenomenological Analysis of a Biopsychosocial Group Intervention for Carers.
Name of Chief Investigator(s): Craig Wilson, Trainee Clinical Psychologist
Dr Susan Turnbull, Academic Supervisor
Dr Lisa Gadon, Clinical Psychologist

Please Initial Below

1	I confirm that I have been given information sheet dated 10/4/2016 (version 2.3) for the above study.	<input type="text"/>
2	I am happy to be contacted to discuss participation in the study via telephone.	<input type="text"/>
3	My telephone number for being contacted is	<input type="text"/>

Name

Signature

Date

Name of Person taking Consent

Signature

Date

Appendix 2.6: Participant Consent Form

Title of Study: Responding to Stress and Distress in Early Onset Dementia: an Interpretative Phenomenological Analysis of a Biopsychosocial Group Intervention for Carers.

Name of Chief Investigator(s): Craig Wilson, Trainee Clinical Psychologist
Dr Susan Turnbull, Academic Supervisor
Dr Lisa Gadon, Clinical Psychologist

Please Initial Below

1	I confirm that I have read the information sheet dated 10/4/2016 (version 2.3) for the above study.	<input type="text"/>
2	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="text"/>
3	I have received enough information about the study.	<input type="text"/>
4	I understand that my participation is voluntary and that I am free to withdraw until the study has been sent for final submission to the university, without giving any reason. Withdrawing from the study will not affect my own or the person I care for's current care or legal rights.	<input type="text"/>
5	I understand that my interview will be recorded on a digital voice recorder and transcribed, and I give permission for this.	<input type="text"/>
6	I understand that members of the Young Onset Dementia Team, the chief investigators, and the University of Glasgow will have access to the personal information that I provide for the purposes of this study only.	<input type="text"/>
7	I understand that my information will be kept in line with confidentiality guidelines, will be recorded anonymously on an electronic database (i.e. my name will not be recorded), and stored securely within the University of Glasgow.	<input type="text"/>
8	I understand that some of what I say during the recorded interview may be used as an anonymised quote when the study is written up, and I consent to this.	<input type="text"/>
9	I give permission for the researcher to inform my GP, members of the Young Onset Dementia Team, and other services that provide input to me (e.g. Alzheimer's Scotland Link-Worker), of my participation and if further support needs are identified.	<input type="text"/>
10	I consent to take part in the above study.	<input type="text"/>

Name

Name of Person taking Consent

Signature

Signature

Date

Date

If, when the study is finished, you would like to receive a short summary of the study findings please tick this box. ☐ If you wish to be provided with a summary, please provide your postal address below:

Appendix 2.7: Interview Schedule

Introducing questions: So why don't we start by you telling me about who you are? Who do you care for? And what about the rest of your family? Check consent forms and query.

Focus Point: To understand carers' experiences of the group
<p>Intro: I'm interested in how you experienced the group. I thought we could start by talking about what it was like for you?</p> <ul style="list-style-type: none"> - What was the group like? How did you find it? How was it for you? - How did you find out about the group? - What parts of the group did you like? What made this likeable? What did you enjoy? - What about the things you didn't like? What made this dislikeable? What did you not enjoy? - What parts of the group were you most interested in? What did you find yourself thinking about in the group? If people were to ask you about the group, what would you say? - Is there anything you hoped for from the group that you didn't get? Is there anything that wasn't addressed that you feel should have been? Would there be anything that would you change? ➤ Was there anything that surprised you? If you were talking to people about the group, what would you tell them that surprised you? - Were you able to attend all sessions? If not, what were the reasons? Would you have liked to? - What things did you know before coming to the group? What wasn't news to you? - How did you find talking in the group? What did you talk about? How was it for you? Do you find talking in groups comfortable or less so? - Was there anything other people said that you found useful/agreed with/disagreed with? What was this? What was it about that for you? - Do you feel that you participated at the right time? When do you feel is the right time? What makes it the right/wrong time? What would you say to others that are thinking about participating?

Linking questions
<ul style="list-style-type: none"> - What were you told about the purpose/aims of the group? - What made you decide to go to the group and keep going?

Focus Point: To identify any influence that group participation has on carers' lives (+processes)	Focus Point: To identify any influence that group participation has on carers' experiences of the caregiving role (+processes)
<p>Intro: Now that you've been to the group, I'd like to find out about your life now. Can you tell me about the impact the group has had?</p> <ul style="list-style-type: none"> - Have things changed for you since participating in the group? - Has anything been worse? Has anything been better? Has anything been the same? 	<p>Intro: I'd like to find out about what it's like caring for [X] after being to the group. How have you found caregiving since being part of the group?</p> <ul style="list-style-type: none"> - Is this a change or is it the same as before being in the group? - Has the group made a difference to your caring role? - What has changed? Has anything been harder? Has anything been easier? Has anything been the same?
Focus Point: To identify the processes, or mechanisms, that account for these potential influential factors	
<p>These will be found through enquiring about the above.</p> <ul style="list-style-type: none"> - What do you think is the reason for these changes? Has there been anything about being in the group that would explain these? What about outside of the group? - What reasons have things stayed the same for you? Has there been anything, good or bad, about being in the group that would explain these? What about outside of the group? - What were the most important things about the group for you? Are they the reasons for things being better/worse? 	

Focus Point: To understand carers' perceptions of dementia following group participation.

Intro: **Now that you've been to the group, what do you think of your family member's dementia?**

After the group: **Are they the same or have they changed?**

- If they have changed: How have they changed? What has changed your view? Both inside and outside of the group?
- If they haven't changed: Can you tell me more?

- **How do you talk to people about your family member's dementia?**

Before the group: **Thinking about what life was like before the group started, what were your thoughts on dementia?** How did you view it? Where do you think this view came from?

Focus Point: To understand carers' perceptions of distress following group participation.

Intro: **One aspect of the group was to help you understand and manage your own and other's distress. Now that you've been to the group, how do you understand your family member and your own distress?**

After the group: **Are they the same or have they changed?**

- If they have changed: How have they changed? What has changed your view? Both inside and outside of the group?
- If they haven't changed: Can you tell me more?

Before the group: **Thinking about what life was like before the group started, what were your thoughts on these behaviours?** How did you view it? Where do you think this view came from?

Ending: Lastly, I would like to discuss how you feel about the support you get.

Support:

- **You mentioned that [people] are around. Who provides you with support?**
- **How do you feel about the support provided?** What have you received?
- **Do you know what to do if you require further support?**

Signposting:

- Query input from Young-Onset Dementia service, GP, and third-sector services (e.g. Alzheimer's Scotland Dementia Link-Worker).
- Signpost where appropriate (e.g. Alzheimer's Scotland, Carer Network, Mental Health), including Samaritans, NHS 24 and Breathing Space.
- If distress present, discuss potential for researcher to follow-up with GP or Young-Onset Dementia service.

End:

- Clean-up question (e.g. **that's all I have to ask, have you anything else you'd like to say, final thoughts or anything we haven't covered?**)

Appendix 2.8: Sample of Participant Transcript - Beatrice

Emergent Themes	Transcript	Comments
	Int: Is there anything that's really stuck with you as, 'that really made a difference, for me'	
I'm not alone	Pt2: the whole lot, just.. the relief to know that, again, I wasn't on my own	I'm not on my own anymore, <u>sense of being with other people who are the same, understand, "been though what you've been through", importance of shared experiences</u>
Other carers understand my situation	Int: okay	
Finding shared experiences	Pt2: [long pause] and just to get in, and... talk and, know that other people, have been through what you've been through and	
	Int: okay. So is that... the conversations happening in the group that were useful	
	Pt2: mmmm, yes	
	Int: okay	
Acknowledging the content but prioritising the conversation	Pt2: oh and also the coursework, emm but the conversations kinda... overtook it sometimes [chuckles]	"and also the coursework" – the coursework was helpful, but not as much as the conversations, sense it had its place but the conversations were the place <u>where changes/learning/emotions occurred</u> "overtook it sometimes" – <u>a back and forth, but mainly communication</u>
	Int: yeah	
	Pt2: is what I'd say	
	Int: were there any conversations that really kinda, stuck in your mind? Can you take your mind back and think...	
Ecological validity (they've tried it, so will I)	Pt2: [long pause] one... that somebody uses a wee blackboard, and everyday changes the day on it	Learning about strategies from other carers, <u>not the nurse, but others that have tried these, ecological validity</u>
Giving shared strategies a try (experimenting)	Int: okay	Noticing what does and doesn't work for her husband with dementia, <u>being honest about strategies, thinking about how they apply to their situation</u> "somebody else tried it and they said it worked for them" – others having success using strategies provided by other carers, <u>sharing in the successes</u>
Sharing in others' successes	Pt2: and the date, and whatever her husband's got... emm, to do that day, didn't work for [Husband] cause he didn't remember where the blackboard would be he wouldn't remember	
Being okay with strategies not working	Int: okay	
	Pt2: but for her it worked and somebody else tried it and they said that worked for them as well	

Appendix 2.9: Example of Emergent Themes with Quotations

<i>Superordinate</i>	1. Becoming more than a group		
<i>Conceptual</i>	1.1 Connecting to other carers		
<i>Subordinate</i>	1.1.1 I'm not alone, people understand		
<i>Participant Meanings</i>	I'm not alone	We're in the same boat (recognising similarities)	Being understood
<i>Transcript Extracts</i>	"you don't meet people without groups like that... especially the age group that my dad is, when you go to... the other groups and things it's all, really, people thirty years older than my dad so you don't, have the same, experiences..." (Adele)	"it's amazing to meet people in the same... situation as you..." (Adele)	"...the nurses will say try this do this but they've all got personal experience, and know understand how you're feeling at the same time and how frustrating it can be at times..." (Adele)
	"... I wasn't, on my own, I wasn't alone anymore" (Beatrice)	"just to meet somebody else, in ma situation" (Beatrice)	"just to get in, and talk and, know that other people, have been through what you've been through" (Beatrice)
	"to not feel alone" (Chris)	"this is where the group really really, works well, cause we are on that sort of same... support level" (Chris)	"being able to tell your own little stories, sad, funny... whatever they were, would help because somebody else could relate to them..." (Chris)
	"one of the things I found out about the group is I'm not alone..." (David)	"..., we're just people like, all the same, well not all the same similar, similarities, but that's where I found the comfortable part..." (David)	"it's the, idea of not being alone, people understand what you're going through..." (David)
	"I just felt, I wasnae alone" (Edith)	"I arrived at the club and, I think, 'these people are in the very same situation as me', and, 'they're probably, got the same worries and frustrations as me..." (Edith)	"people don't understand that where people in that group, who are dealing with the same things as what I'm dealing with, understand 100%, about their worries, and how they're managing to cope and different things, and I felt the group was, really beneficial to me" (Edith)

Appendix 2.10: Major Research Project Proposal

Abstract

Family members of people with a diagnosis of dementia are fundamental to supporting their cared-for live at home. Although this can be a positive experience, psychological distress can occur as a result of their caring role(Scottish Government, 2010). Various group interventions have been used to reduce the negative effects of caregiving. Research with caregivers of people diagnosed with Early-Onset Dementia (EOD) is limited, and despite the differences between older and younger caregivers, both populations are often grouped together when conducting research. Furthermore, research into how interventions work, including what processes mediate effectiveness, is limited within EOD caregiving populations.

Aims: The proposed study aims to understand how carers experience a group intervention that focuses on some of the most difficult aspects of caring - behaviours that challenge. Of particular interest is whether this can inform our understanding of the processes that account for these experiences.

Methods: Following semi-structured interviews, an Interpretative Phenomenological Analysis approach will be used to analyse participants' experiences.

Applications: The study will add to the growing evidence base in an under-researched population and allow services to tailor interventions.

Introduction

Around two-thirds of people with a diagnosis of dementia live at home (Livingston et al., 2014) and carers are fundamental in the maintenance of this arrangement. During this time, carers can experience psychological difficulties from their caring role (Scottish Government, 2010), impacting their wellbeing, and increasing admission rates to care facilities (Yaffe et al., 2002) and mortality rates (Brodaty et al., 1993) for the person with dementia.

Caregiving for Early Onset Dementia

Both younger and older caregivers can experience similar difficulties (Roach, 2008). For example, caregivers for people who are diagnosed before the age of 65, termed Early Onset Dementia (EOD), can experience increased levels of burden, depression, stress, and health difficulties as a result of their caregiving role (van Vliet et al., 2010).

Similar consequences are experienced by carers of those diagnosed after the age of 65 (Brodaty & Berman, 2008), termed Late Onset Dementia (LOD). These can arise from difficulties that occur within the dementia process, such as the deterioration in communication (Braun et al., 2010). Of importance is the presence and management of behavioural difficulties (Brodaty & Berman, 2008), which are a significant risk factor for adverse outcomes identified above (de Vugt et al., 2006).

Despite the commonalities within the caregiving experience, there are important distinctions between these groups - people with EOD have more varied presentations, more severe and pervasive symptoms, and increased behavioural changes (Mendez, 2006). EOD caregiver's circumstances can be different due to their life-stage (Erikson, 1963) and so have additional challenges to overcome, such as having to abandon mid-life projects (Ducharme et al., 2013). They can have dependents living at home who can find the change in relationships distressing (Roach et al., 2008) and families are more likely to face financial and employment difficulties (van Vliet et al., 2010) than LOD caregivers. Thus, younger caregivers represent a separate population from older caregivers.

Caregiver Interventions

Interventions for dementia caregivers aim to provide knowledge, understanding, and skills for facilitating the caregiving role. Meta-analyses (Brodaty, Green, & Koschera, 2003; Sörensen & Pinquart, 2006) have shown that caregiver interventions reduce the adverse effects of caregiving to a limited extent: effect sizes were small-to-moderate; evidence quality was mixed due to content and technique variability; and several

studies had small sample sizes. Intervention type was important, with studies supporting the use of psycho-educational interventions (Sörensen & Pinquart, 2006). It is, however, difficult to ascertain the effectiveness of interventions with EOD caregivers as study samples often combine younger and older caregiver populations (Brodaty, Green & Koschera, 2003).

Although useful, quantitative studies of effectiveness do not offer explanations as to the specific aspects of, or processes within, the intervention that may mediate reductions in adverse caregiving effects. This is partly due to the complexity and multi-componential constitution of interventions (Sommerlad et al., 2014). Several processes within interventions have, however, been proposed. In a systematic review of UK-based interventions for all types of carers, discussing the caring role whilst being recognised, validated and normalised (Victor, 2009) helped facilitate positive outcomes. Other processes included the change from emotion-focussed to problem-focussed strategies (Lockeridge & Simpson, 2012), carer attitude (acceptance of the diagnosis and caring situation), access to therapists for sharing concerns, and use of cognitive reattribution techniques (Sommerlad et al., 2014). This research has primarily focussed on LOD populations - research with a specific focus on EOD caregivers is required.

In summary, ongoing research into the effectiveness of caregiver interventions continues to show improvements for caregiver outcomes (Livingston et al., 2014). Due to the differences between older and younger caregivers, it cannot be assumed that interventions will be appropriate or beneficial for younger carers. Further research is warranted into interventions to support an EOD caregiver population.

“Stress & Distress in Dementia” for Carers Group

NHS Education for Scotland developed training for staff and carers to help develop an awareness of, and learn strategies for, managing their own and their cared-for's distress (Thurlby & Whitnall, 2013). Designed to be flexibly used with both caregiving populations, the package covers aspects of caregiving such as recognising distress,

emphasising caregiver 'personhood' (Kitwood, 1997) and developing coping strategies to meet unmet needs that underlie distress presentations (James, 2011). The group is currently being evaluated for effectiveness using a quantitative approach within NHS Lanarkshire.

Aims

The study aims to explore how EOD caregivers experience the group. Of particular interest are the experiences and processes within the group that participants perceive as having contributed to their caring role.

Research Questions

The study asks how carers experience the group and how this may influence their caring role following participation in the group. The study will investigate what experiences within the group they perceive as having contributed to this. The study will explore these through the following objectives:

- To understand carers' experiences of the group;
- To identify any influence that group participation has on carers' lives and experiences of the caregiving role;
- To identify the processes, or 'mechanisms of change', that account for these potential influential factors; and
- To understand carers' perceptions of dementia and distress, either from themselves or from the cared-for family member, following group participation.

Plan of Investigation

Design

The present study will use a qualitative research approach, and a number of analytical methods were considered. Both constructivist Grounded Theory (GT; Charmaz, 2006) and Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) can

facilitate insight into processes within an experience (Braun & Clarke, 2013); however the former does so for the development of theoretical explanations (Chamaz, 2006). IPA focuses on understanding people's lived experience and the meanings they derive from them to understand the world (Smith et al., 2009). As the focus of the study is on the individual's experience of the group, IPA was chosen as the most suitable method.

Participants

Participants will be family members of people with a diagnosis of EOD who have participated in the carers' group. IPA requires purposeful sampling (i.e. they offer insight into experiences) with adequate homogeneity (i.e. participants having similar characteristics) for detailed exploration of a phenomenon. Although there will be variation between carers in their relationship to the cared-for person, duration of caring role, severity of the care-receiver's dementia, and level of support received from services, inclusion criteria will aim to facilitate a pool of participants who share enough similar characteristics.

Inclusion and Exclusion Criteria

Participants must (a) be a family member that provides care to the person diagnosed with EOD (spouse, parents, children, etc.); (b) have completed the group between 1 and 12 months prior to interview involvement; (c) have attended at least four group sessions out of seven; (d) have adequate command of spoken English; and (e) be over 16 years of age.

Participants will be excluded if they (a) attended a group out-with defined timescales; (b) have attended less than four sessions; or (c) are under 16 years of age.

Using these inclusion and exclusion criteria will allow for participants to have been exposed to sufficient group experiences, offer opportunity to implement the training, and have sufficient recall of the experience. Potential participants will be identified from discussions with EOD staff. Interviews will be conducted over a 10 month period,

which allows for approximately seven groups to be finished with a potential pool of 35 carers for the study.

Justification of sample size

Guidance on sample sizes indicates that between four and 10 interviews are appropriate for IPA (Smith, Flowers & Larkin, 2009) as fewer participants allows for a concentrated focus on human experience. As this experience is often complex, sample size selection should take several factors into consideration (Smith, Flowers & Larkin, 2009). These include the depth of experiences expressed in individual interviews, the level of analytic process undertaken, and constraints placed on researchers (Smith & Osborne, 2008). Also of importance is 'saturation' of themes between participant experiences, which means that commonalities and discrepancies in themes become consistently identified (Smith, Flowers & Larkin, 2009). Thus, the final study sample size will be within this range, and sampling will cease when no further meaningful themes become identified.

Research Procedures

Recruitment and Consent (Figure 1)

During routine follow-up with Young-Onset Dementia (YOD) staff, previous group participants will be given information sheets (Appendix A) and asked for consent to contact (Appendix B). The researcher will contact potential participants to discuss the study further and to arrange interviews. Before the interview, study information will be reviewed and formal written consent taken (Appendix C). For current and prospective groups, information sheets will be provided at penultimate group sessions. The researcher will attend the final session to discuss the study, gain formal consent (Appendix C) and set provisional interview dates for around one month later. This will be confirmed a week prior to the interview. Study information will be reviewed and written consent renewed prior to interview commencement.

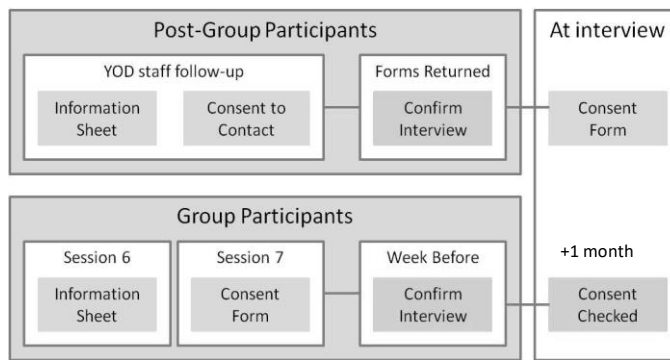


Figure 1. Proposed recruitment pathways.

Interview

Semi-structured interviews will be used, which are anticipated to last up to an hour. Demographic information will be collected prior to interview commencement (Appendix D). An interview protocol (Appendix E) has been generated through consultation with members of the YOD team and will be used flexibly during interviews. Open and prompt questions will be used to facilitate exploration of key content to promote rich data for the analysis (Smith & Osborne, 2008). Participants will be offered breaks and the opportunity for debriefing. Permission will be sought from participants to use verbatim accounts in the final report.

Settings and Equipment

Staff from the Young Onset Dementia (YOD) Team, Lanarkshire, will be given study packs containing information sheets and consent forms. Interviews with carers will be carried out by the researcher within a clinic room in the same location as the group where possible. A digital recording device, with relevant transcribing software on an encrypted laptop, will be required.

Data Analysis

Interviews will be transcribed verbatim, anonymised, and analysed using IPA. Smith and colleagues (2009) emphasise conducting an IPA flexibly and in a non-linear fashion, whilst maintaining several underlying processes and principles. These include shifting between understanding the participant's experience and the psychologically-focussed

meaning-making of the researcher within the participant's experience (Smith & Osborne, 2008), within the context of individual experience and shared experiences and moving from descriptive to interpretative comments (Smith et al., 2009).

Each transcript will be read several times to allow immersion in the data (Smith & Osborne, 2008), and comments will be noted and coded; focussing on understanding of the participant's lived experience. This will culminate in the development of emergent themes, which will be mapped with similar themes. Participant interviews will be considered individually with this process before themes are compared throughout all interviews. This will culminate in a cluster of main- and sub-themes.

The study aspires to improve validity and quality of results using identified principles within qualitative research (Yardley, 2000). This includes keeping a reflective diary to delineate subjective views of the researcher (Smith & Osborne, 2008) from carer experiences, and employing a thorough and systematic analysis. Transcription accuracy and inter-rater reliability for theme robustness will be assessed by members of the research team and selected peers within the doctoral training (Appendix H).

Ethical Issues (Appendix F)

Participant Issues

Within similar research, expressions of distress can occur (Wawrziczny et al., 2014) as participants may be discussing upsetting situations. The researcher has therapeutic training and experience working with clients who express distress and will respond to distress in a supportive manner whilst monitoring potential risk issues. Should participants show distress, the researcher would acknowledge and discuss this with the client, seeking consent to share this with members of the YOD team should they still be open to the team. Carers, including those who are not actively supported via the YOD service, would be encouraged to contact their General Practitioner and signposted to services should they feel they require further support. Group sites will be familiar to

carers and are adequately staffed. Clients will be reminded of their ability to stop interviews briefly or withdraw entirely. Should the latter occur, participants data will be removed from the study. Participants will be advised that they can withdraw from the study until final submission.

Researcher Issues

The researcher maybe exposed to distressing information. Regular supervision arrangements will be arranged with both academic and field supervisors, with the potential for weekly meetings with the field supervisor during a six-month placement with the service. Health and safety policies will be adhered to and YOD staff will be aware of the interview schedule. The researcher will discuss potential safety issues with staff beforehand and conduct risk assessments should they be required. Domiciliary visits will not be conducted.

Ethics and approvals

The study proposal has been blind reviewed by a member of the University of Glasgow Doctorate in Clinical Psychology academic team before being submitted to the NHS Lanarkshire Clinical Quality Group, an NHS Research Ethics Committee (N-REC), and NHS Lanarkshire Research and Development for approval.

During the study, all information will be stored securely within a training folder on the encrypted laptop and the researcher's University of Glasgow secure drive. Carers will be given unique identifiers to preserve anonymity, and access to recordings and transcripts will be granted to the research team and reviewers (Smith et al., 2009), in line with relevant data protection and confidentiality policies. After conclusion of the research, the data will be retained by the University for a minimum period of ten years (University of Glasgow, 2014) with the exception of interview recordings, which will be deleted.

Financial Issues

Equipment required for the proposed study will be acquired from the Institute of Health and Wellbeing. Other financial costs will include stationary and printing facilities for the study pack (see Appendix G).

Timetable

The study proposal will be submitted by the February 1st, 2016, with final approval by May 16th. Interviews will run from September/October 2016 to May/June 2017.

Transcription and analysis will be conducted during this period with final submission of the thesis during July 2017.

Practical Applications

The study will aim to provide insights into areas where interventions with this client group need to address to maximise the positive impact that interventions have.

Furthermore, the study will further the growing evidence base that is exploring the processes of change within carer's experiences to allow services to tailor interventions.

This is an under-researched population and a unique study in research dominated by studies with older caregivers.

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